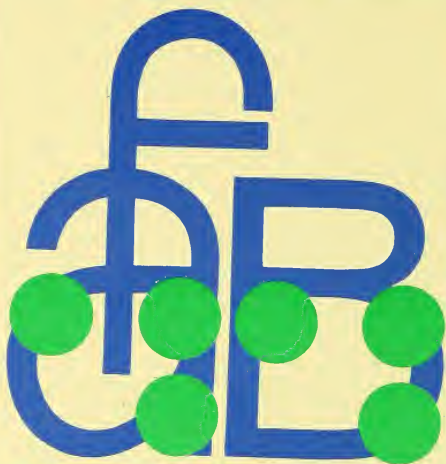


# **Access** **to Dignity** VOLUME 2

Frances G. Berko, J.D., M.A.  
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# **Access to Dignity**

Formal presentations made between  
January 1982 through March 1983

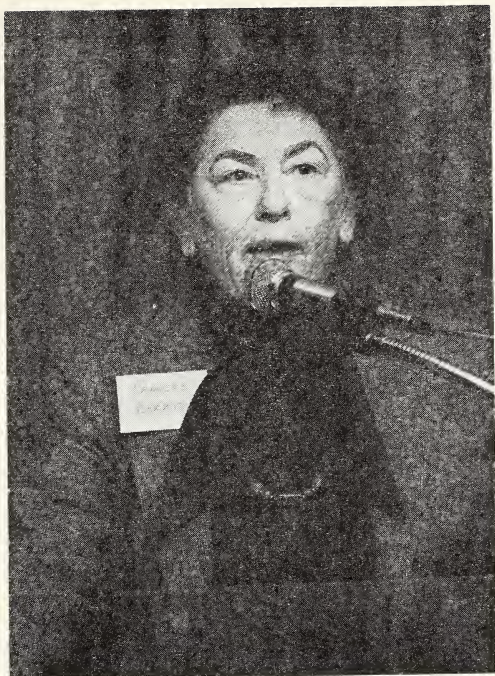
by

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# Contents

	Introduction.....	3
1	What Is the Advocate's Office.....	5
2	Public Testimony before Legislative Committees.....	31
3	Education.....	55
4	Employment.....	70
5	Councils on the Disabled.....	81
6	Introduction to Legislative Process.....	88
7	Accessibility Through Awareness.....	108
8	Normalization.....	117
9	Early Intervention.....	133
10	Rehabilitation.....	142
11	From the Advocate's Desk.....	153





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## Introduction

The 1982 publication of "Access to Dignity" was an integral part of the effort to gain a legislative base for the New York State Office of Advocate for the Disabled. While that initial publication was never envisioned as the first in a series of such publications, it became apparent, in reviewing the responses to the volume, that "Access to Dignity" was a helpful tool in assuring that the public positions of the state advocate could be referenced accurately and consistently by interested persons throughout the state.

"Access to Dignity, Volume II" covers the period from January 1982 through March 1983, with some notations on legislative/administrative actions which occurred in the

Spring and Summer of 1983. While most of the advocate's public appearances are noted herein, this volume is not intended to be a complete record of all statements and all appearances. The latter are recorded in their entirety in this office's annual report. While every effort is made to avoid duplication of presentations while still keeping the context of what is said before each group understandable, a notable exception is the reprinting of the text of the speech delivered to a group at the annual meeting of the New York State Association of Community Residential Administrators. The Berko interpretation of normalization theory was printed at length in Volume I and is partially repeated elsewhere in this edition. However, it is so fundamental to understanding the specific issues raised throughout this volume that repetition seems most appropriate. In addition, from the viewpoint expressed herein, the integration and implementation of normalization theory must occur before the achievement of equity for all persons with disabilities can be expected.

This volume is the product of the entire staff of the State Office of Advocate for the Disabled. While most, if not all, concepts originate with the advocate, no speech text is ever final without input from Paul Smith and Robert Boehlert. In many cases, Rosemary Lamb, John Tauriello and Roxane Offner also comment and make additions. Equally essential, although less direct are the contributions of Charles Lobosco and Mel Seamans who cull necessary data from our information and referral system and Norma Modaffari who provides the critical budgetary analysis. The true heroine of each speech is often Darlene Ego Stefani, my secretary, who must translate as many as six different, illegible handwritings super-imposed on her typing to produce the final text. Lynne Marino faces similar challenges with the texts of legislative testimony. Finally, no one but I who spent two solid days in final editing can appreciate the contributions which Yvonne Williams and Laura Eisler made to the production of this volume. I humbly thank my staff for making me look so good.

Frances G. Berko  
July 1983

# **What is the Advocate's Office?**

\*\*\*Remarks made at Meeting of Councils on the Disabled,  
January 13, 1982, Albany

You have just heard that we are into many things, legislation, job development and employment, budgetary problems, agency structure, information and referral, housing, transportation, and on ad infinitum. We have no authority, just the power of persuasion. We are flexible. We try to tell it as it is. Within budgetary and personnel limitations, we are committed to do what needs doing.

However, all of this is meaningless without you. Aside from citizens with disabilities themselves, you, as client advocates, are our best agents for change. You have knowledge of the client's needs and of objective resolutions to those needs which are programmatically and economically viable. You live in the real world. You have been trained to seek real resolutions to problems. You demonstrate your training and experience exceedingly well. Your strengths -- and they are many -- at times need feedback and support; the need for reinforcement is not limited to the clients. We all need to be told "Good. That's right. Keep it up."

Our purpose here today is not only to provide such reinforcement, but also to tell you that your strong position as agents for change now has an ally -- that there is a resource available which can attend to issues beyond your domains.



Now that you know, it is your responsibility to use it, to teach your clients and their families to use it. Without your input, without hearing from you how it is really coming down and what the real world needs by way of resolutions, we fail in our mission. By the same token, you have a responsibility to come to us. If you do not assume this initiative, we cannot know how it is, regardless of what we do.

And so the bottom line of the past hour or more is a plea and a charge to you -- please call us when you hit that proverbial stone wall. Who knows, we may be able to strengthen your position as the primary client advocate. At the very least, similar problems reported from various parts of the state can document the need for changes which we all may have recognized for years.

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\*\*\*Presentation to the Epilepsy Society of the Capital District, March 2, 1983, Albany

My first client was a man who had a seizure disorder. In every clinical experience I have since had, I was responsible for at least some phase of programming or advocacy among citizens with seizure disorders.

Often in the course of years, I dreamed of talking to a group of people whose interests focused on epilepsy and related disorders. I would love to exchange some concepts learned through experience and not found in any book. I would love to ask questions for which I have never been able to find an answer. I would love the luxury of reviewing non-medical components of programs and services to citizens with epilepsy, to study what we are doing right and what we may be overlooking.

However, my charge tonight is not in the capacity of clinician but, as the State Advocate, to describe to you what the Advocate's Office does and how it can be of assistance to you.

Simply stated, the Advocate's Office endeavors to be a broker between the state agencies charged by law with the

responsibility of direct service, community service providers and citizens who may have one or more disabilities.

Who is this citizen with disabilities? While New York State has yet to adopt a uniform statewide definition of such citizens, our office is functioning on the basis of the federal definition set forth in Title V of the Rehabilitation Act of 1978. Needless to say, persons with developmental disabilities are a substantial subgroup within the overall definition.

Based on a perception that the needs of their constituencies will be lost, some provider groups have reservations about such a statewide definition. Our experience has indicated the opposite. Much needed legislation fails to get proper attention because the absence of a suitable definition of the population to whom it pertains leads to an inability to define the proposal's fiscal impact. On the other hand, other disability group advocates need to better identify the substantial barriers which the disability places upon the growth and development of the individual. Persons with seizure disorders may fall within this category.

Over the years, several things have become increasingly apparent. Persons with varying disabilities have common barriers to full integration into the daily life of their chosen community. Unless there is ongoing communication between persons of different disability groups, an individual of one disability feels that his disability is unique, and the biases and barriers which are met in trying to live within the community are issues related only to that individual or individuals of that disability group.

Each individual group goes to the legislature to meet their own needs, which are really needs held in common with the larger group. In so doing, they not only do not have the political clout to get the job done, they also confuse the legislature by using different terminology for the same goal, thus providing a perfect cop-out not to do anything.

Understanding how government works, which buttons to push and when, is of maximum importance to goal achievement.

The function of the Advocate's Office is that of systems advocacy, especially as it is differentiated from citizen or

client advocacy. Client advocacy is a function of many other agencies, both governmental and voluntary. Our function is to try to make the system, or what exists, work to achieve current and future needs of citizens with every type of disability. If what exists no longer seems viable to meet current or future needs, we then can act as agents for change. Needed change may require administrative, legislative or judicial action.

Personal opinion further dictates that a systems advocacy office can be most effective when it serves as a catalyst for networking diverse groups concerned with the same issues.

To make what the Advocate's Office does more clear, we have identified five major areas of immediate concern: information and referral, community development, legislation, public awareness and employment development (particularly in the private sector). Added to these is a category known as special projects. Special projects include housing, transportation, Social Security, the impact of federal budget cuts and any other temporal issues that may arise.

Each of these areas is far more complex than is initially apparent. For example, within six months of going to work in Albany, it became abundantly apparent to me that perhaps the greatest need in legislation concerning issues related to citizens with disabilities was not in the area of more laws. It was in the area of making all citizens, all those interested in these issues, more knowledgeable about the legislative process. Both in 1981 and 1982, the Advocate's Office sponsored legislative workshops bringing together representatives from state agencies, a wide variety of service provider groups and all types of citizens with disabilities for two days.

Another area of legislative work concerns our charge to prepare a legislative package for the governor to be introduced at each legislative session. Parenthetically, it should be noted that in each such session over 2,000 bills relating to disability issues are introduced. Of these only a very small fraction are passed into law. In the 1982 session, 57 such bills finally became law, making it an historic year in legislative annals in relation to disability issues.



For the past two years, the Advocate's Office has developed a very small, generic legislative package containing three or four bills that would have major impact on all persons with disabilities statewide. At the same time, the office expends equal effort in supporting those bills of merit proposed by other state agencies, legislators or various organizations throughout the state. It was, therefore, with great disappointment that, in our most successful legislative year, the non-driver identification bill, which is an initiative of the Department of Motor Vehicles, failed to get out of the senate committee, despite the interventions of myself and the director of the State Office for the Aging (Editor's note: now Chapter 295 of the Laws of 1983).

It also has become increasingly obvious that more laws on the books may not be the primary need of persons with disabilities in New York State. Increasingly, attention has to be paid to departmental regulations, conflicts in standards and criteria and general snafus in the established delivery system. Of high priority are community development, outreach into minority groups, coordinators of student activity on college and university campuses, labor market initiatives, job training, public awareness and public education. However, maximized focus on these areas can achieve deserved results only when networking is fostered and strengthened among the various groups concerned with disability issues. Every effort is made to spread the information through publications, either in pamphlet form or in "The Advocate," so that these efforts can be duplicated throughout the state. If you are not now on our mailing list, a request from you is all that is required.

In my estimation, an office such as ours would not be necessary if issues related to citizens with disabilities were in the mainstream of governmental decision-making. Unfortunately, they are not. While Governor Carey probably did more for citizens with disabilities than any combination of previous governors within my memory, these issues and his resolutions were "added on" rather than totally integrated into economic and cultural policy-making. Please believe me, this is not a criticism. The more you know the extent to which

Governor Carey has shown he cared, the more you admire his administration.

However, looking to the future, one of the goals of Governor Cuomo, who is deeply committed to issues related to disabilities, is to integrate issues related to citizens with disabilities into the mainstream. To that extent, the Advocate's Office has sought to become an integral part of the various advisory councils related to citizens with disabilities.

Issues related to citizens with disabilities are infinite, as are issues related to all citizens. In my lifetime, every need of every citizen will not be met. Personal philosophy dictates that when needs are identified you actively pursue those needs for which there is a probability of winning, while at the same time you adequately prepare for successfully meeting other identified needs in the future.

Such needs-identification occurs through many sources. One valuable source is our own information and referral system. The Advocate's Office maintains a toll-free number (800-522-4369) through which any citizen residing in the state can call for information and advice regarding their rights and how to manipulate the established delivery system. In cases where the person answering may not have the desired expertise, the specialist on staff with that area of expertise will either speak to you or call you back.

The Advocate's Office has no authority other than the power of persuasion. On a statewide basis, existing inequities in the established service-delivery system must be identified for appropriate correction. Through our 800 number we can also advise individuals as to what they need to do to obtain their rights in the system as it exists today.

*(Similar comments presented to the Epilepsy Society for Social Services, Inc., February 22, 1982, Albany).*

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\*\*\*Remarks sent to International Association for the Scientific Study of Mental Deficiencies, June 1982, Montreal, Canada

## Federal

It is estimated that there are 35 million persons in the United States who have disabilities. There is much confusion, even among people who use this figure constantly, as to whether this 35 million represents only persons with physical disabilities, or whether those with mental retardation, alcoholism, drug addiction and other mental health and developmental disabilities, or even the frail elderly, are also included in this count. This lack of reliable information concerning the incidence of disability is but a minor factor in the current nationwide ambivalence towards issues related to persons with disabilities. This ambivalence, in and of itself, represents a reversal in four decades of national policy which equate resolution of these issues, at least in rhetoric, with "apple pie and motherhood."

Although most service providers would attribute this apparent regression to the present national administration, historic perspectives render alternative views which seem more significant as guidelines for future action. In the period immediately following World War II, there was a concerted movement to integrate those who were disabled into the mainstream of society, particularly in the labor market, through initiatives paralleling programs and services available to disabled veterans. For example, in 1946 the Vocational Rehabilitation Act was revised for the first time in its 25-year history. During the Eisenhower administration when emphasis was increasingly placed on research -- especially in areas of prevention, staff development and program development -- a provider pattern began emerging which can be best typified by the phrase "going where the bucks are," meaning that the nature of program emphasis seemed to shadow the funding mechanisms, rather than vice versa.

Concomitantly, the growth of concerted consumer movements, particularly among parent groups which soon formed themselves into segregated, political action provider groups focused on the needs of a particular disability group, and the decrease in mortality rates due to gains in medical re-

search and care markedly altered both the nature of the populations to be served and the types of relief sought.

This two-pronged reality (to develop programs where funding mechanisms existed and to revise existing programs requested for populations for whom such programs were never designed) was met in the Kennedy and Johnson administrations by increasing funding, as well as the size and complexity of bureaucracies to administer such additional monies. This course only reinforced the two concomitant patterns that emerged in the fifties. As far as disability issues were concerned, neither administration encouraged the development of policies and programs based upon equity between citizens with disabilities and all other citizens. Rather, such programs were developed for "humane" reasons, and not out of consideration of potential productivity and contributions toward the gross national product. By the late sixties, chaos had developed which resulted in new vocabularies being superimposed upon self-fulfilling prophecies of failure. Such words as "cost-effectiveness," "accountability," "standards," "monitoring" and "program planning" were added to the professional and administrative jargon without any real pause to review the conceptual frameworks upon which they were being imposed. This decade of "consumerism" and "The Great Society" questioned neither the propriety of accepting the needs of parents as identical to those of their offsprings, nor the programmatic concept of services providers as the ultimate solutions.

Civil rights for persons with disabilities hallmarked the legislative initiatives of the seventies. Laws such as Public Law 94-142, which guaranteed education to all children with handicapping conditions, preferably in the least restrictive environment; the Rehabilitation Acts of 1973 and 1978, particularly the provisions of Title V and the Developmental Disabilities Act which created the Developmental Disabilities Protection and Advocacy Systems, combined to represent what was thought to be the ultimate warranty that disabled persons would achieve first-class citizenship. The series of federal court decisions and statutes mandating deinstitutionalization added to this constellation. All of these



efforts were initiated by grass-roots movements -- unique partnerships among professionals, organized parent groups and service providers -- with minor, if any, input from adults who had disabilities. Compromises were wrought that often resulted in ambiguous language which would later have to be defined in regulation. Although blue-ribbon panels were assembled -- at tremendous costs -- to clarify ambiguities, too frequently light was shed only on the fragilities of the partnerships' earlier compromises.

The positive impact of all such endeavors can never be underrated. In fact, it would be a disservice to attempt to enumerate the gains in programs, services, trained professionals, new alliances and technology which resulted because possible omissions may diminish the totality. However, it must be noted once again that these initiatives were, for the most part, added to what had previously existed without adequately reviewing years of documentation to evaluate the extent to which prior legal mandates were appropriate for addressing present and future needs. Further, the new laws seemed to be based on a philosophy that a national policy of humane, equal treatment for all persons with disabilities overrode the preparedness of individuals, local government and technology to deliver what was mandated. No provisions were made to measure the effectiveness of these new laws at some future date. For example, there appears to have been no studies to compare the placement rate of students with disabilities in average public school classrooms to the tremendous growths in special education facilities, or to compare placement rates of disabled workers in competitive employment with the vast expansions of sheltered workshops. At the same time, parent-professional initiatives appeared to be more institutionalized and polarized with regard to strategies for implementation.

Beginning in the late 1960's, innovative use was made of the federal judiciary system to achieve mandated services. Following the enactment of the various civil rights legislation, class-action suits multiplied annually. As time passed and the incidence of class-action suits used as an alternative to legislation increased, a perception developed that this useful tool

was frequently being used as an instrument of initial rather than last resort. As a result, mandates for services and programs for specific groups of persons with disabilities outstripped the technological and financial resources of local government. Continued forays into the courts also broadened the inequities among disability groups, thus alienating the support of both the general public and the specific populations which should have had a vested interest in the promotion and extension of such mandates.

Although diverse voices-in-the-wilderness opposed various aspects of these implementation strategies, no apparent cohesion or even communication existed between these forces. One such force was composed of persons with disabilities who achieved sufficient cohesion among themselves to effectuate a White House Conference on the Handicapped in 1977, but they could not achieve a melding of viewpoints at this historic occasion sufficient to sustain a real politico-social force in the years to come. Concurrently, however, sundry factions in attendance formed new coalitions of varying stability, some of which crossed disability groups. This inability of persons with disabilities to unite into a single political force resulted in an "open field" for service providers to define who is disabled and what services persons should receive, depending on where the funding and the provider's vested interest lay.

Normalization theorists might be considered a second force. While the theories propounded by Wolf Wolfensberger are the most widely known of this group, his concepts may not represent the mainstream of today's normalization concepts.

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## **New York State**

Developments in New York State during the same time period have paralleled those on the federal level, often exceeding some of the initiatives undertaken by other states.



Beginning in 1975 with the election of Hugh L. Carey as governor, statewide initiatives which affected those with disabilities included:

1. The governor's decision to sign the consent judgement in the Willowbrook class-action suit, rather than delaying action through the judicial appeal process, not only resulted in a vast commitment of state financial resources to the task of deinstitutionalization (approximately \$900 million annually from state tax revenues), but also triggered the greatest explosion in local programs and services in the ensuing seven years ever experienced in this state.
2. The division of the Department of Mental Hygiene into the practically autonomous Offices of Mental Health, Mental Retardation and Developmental Disabilities and the Divisions of Alcoholism and Alcohol Abuse and Substance Abuse Services, permitted a concentrated focus on each of these discrete populations.
3. The New York State law paralleling Public Law 94-142 and the accompanying regulations established a pattern of growth and refinement of educational services for children with handicapping conditions in this state, independent of federal policies or degree of financial support.
4. The expansion of state agencies with primary responsibility for programs and services to various groups of disabled persons, with the authority to establish programs and services in areas where no local provider was willing or able to undertake such services, resulted in the creation of an accountable group of local providers across the state. These providers offered needed services at the community level to ever-increasing numbers of citizens and, at the same time, maintained a cost containment structure despite inflationary rises.
5. A policy decision required generic agencies like Social Services, Housing and Community Renewal, and Health, to assume responsibilities for special programs and services for the disabled which fell within their overall responsibilities. One early manifestation of this policy was the disbanding of the Governor's Committee on Employ-

ment of the Handicapped, since employment and training of all persons falls within the domains of several other generic state agencies. The governor then issued a series of executive orders to assure that expansion of employment opportunities for persons with disabilities was a clearly understood policy of his administration.

6. The hallmark of the Carey policy towards persons with disabilities may be found in his often-repeated statement that the key to full integration of persons with disabilities into community life is employment. Not only are the disabled a specifically mentioned class in the state's affirmative action policies and mandates, but 700 jobs were created in state employment for persons with physical and intellectual disabilities who were unable to take civil service examinations. At the same time, a variety of accommodations in the administration of examinations were effected by the Civil Service Commission to insure that qualified persons with disabilities could be fairly tested. Legislation was also enacted to assure parallel initiatives in county and municipal civil service.
7. Despite Governor Carey's repeated urgings, the State Legislature has thus far failed to enact civil rights legislation for the disabled (Editor's note: now Chapter 720 of the Laws of 1982), even though such persons are mentioned as among the classes of persons protected from discrimination in New York Human Rights Law. There are many reasons for this failure, not the least of which are the problems of the vested interests of provider groups and various groups of disabled persons who seem unable to unify their initiatives on this issue. In fact, each time such legislation is considered, it is perceived that representatives of service providers are conspicuously absent from the halls of the legislature, while representatives of various persons with differing disabilities each plead for their own needs, often to the exclusion of issues of concern to those with other disabilities. Such performances have also been witnessed in other initiatives which have thus far failed to gain legislative approval, such as support and further expansion of independent living programs, job security in

state employment or preschool education for all children with handicapping conditions.

8. The creation of the Commission on Quality of Care for the Mentally Disabled as an independent agency to monitor the state's service-delivery systems in mental health, mental retardation and developmental disabilities is another noteworthy initiative. Here again, vested interests seem to have prevented including all aspects of the delivery system within its purview, i.e., those which are not the direct responsibility of the Offices of Mental Health and Mental Retardation and Developmental Disabilities. Additionally, the commission does not have the present resources for such comprehensive monitoring. Legislation presently pending would empower the commission to promulgate uniform standards, but such legislation would appear ineffective without a significant expansion of responsibilities and resources. Most recently, the federally mandated Protection and Advocacy System was placed under the aegis of the commission, which thereupon developed, mainly through contractual arrangements with independent providers, a model regional system of legal and client advocacy which has become a future service goal for all persons with disabilities.
9. In 1979, a law was enacted empowering counties and certain municipalities to create councils on the disabled as an advisory arm to local legislatures. As the fiscal restraints of government to provide human services in the coming decade become increasingly apparent, so grows the importance of this legislation in maintaining currently needed programs and services for persons with disabilities. Such councils have the potential to develop into the type of unifying force which is needed to create relevant, affordable services in the coming decades.
10. The Council on Children and Families, created to provide interagency linkages in order to define and resolve issues related to New York State children and their families, has done much in the development of programs and services for children with handicapping conditions and their families. This legislatively based council, consisting of the

human service commissioners and chaired by the secretary to the governor, is more than a systems advocacy agency. It has the authority to initiate investigations and detailed documentation of issues and to develop needed services where the responsibility for such services is not clearly within the legal mandates of one specific human service agency. For example, the repartition of out-of-state students with handicapping conditions into appropriate program was developed for New York State by this council, which is charged with the plan and the responsibility for its coordination and implementation.

11. In preparation for the 1977 White House Conference on the Handicapped, statewide efforts were made to ascertain grassroots issues and needs. When the New York delegation returned from Washington, a principal concern was that tangible, permanent initiatives result from such efforts. In 1977, Governor Carey created by executive order the Office of Advocate for the Disabled as an arm of the Executive Chamber.

### *What is Advocacy?*

As the years passed following creation of the Office of Advocate for the Disabled, confusion increased over the meaning of the term "advocacy." According to any theoretical definition, advocacy is a specifically assigned, formal role which is separate from the service-delivery system upon which it is to have an affect. The confusion arises when persons working within that service-delivery system must negotiate for change within the system in the course of performing their job responsibilities. As demands for accountability, time management and outcome-oriented goals upon such persons increased, the need arose for a label to account for the large blocks of time expended in getting the system to work for individuals. A label was needed to denote the intangible efforts required to achieve tangible results, especially after the introduction of behavioral objectives and its successor; the individual program plan, both of which required concrete measurements of what was done for the individual. Thus, what individuals and agencies always considered integral to



their responsibilities continued to be done only when it was called by a new name, "advocacy."

"A rose by any other name..." is a valid thought. What difference does it make what you call it? The initial difference is found in the frame of reference of salaried personnel within the service-delivery system and the resultant effects on the job performance on behalf of the client. Some self-styled advocates become so involved in the process of changing the system that they lose sight of their responsibilities the client and the agency by whom they are paid. Frequently, it is unclear whether the desired change is for the betterment of the client or the staff person. Even when client betterment is clearly sought, changing the system often appears to override training the client to function more adequately within the system.

For example, an employee who describes an improved strategy in agency function to a manager is simply performing a responsibility of employment. A case manager who calls together representatives of four other agencies to devise an appropriate program plan for the client is simply doing the assigned job. An agency director who comes to Albany to seek better program funding is dutifully exercising his functions as a manager.

Another commonly misunderstood function is information and referral (I and R). Information and referral systems are not functions of advocacy, but they are valid, necessary functions falling under some other categorical responsibility. Often they are attached to an advocacy function as a natural concomitant; this usually occurs for want of any other place to put this needed function.

However, I and R can function as an adjunct to a systems advocacy agency if its primary function assists in identifying the gaps and breakdowns within the service-delivery system. This model informationally networks the client to the established delivery system, as opposed to providing direct linkages or transitional assistance to needed services. Upon occasion, I and R systems are required to assist the client in identifying what services are needed, but these time-consuming exceptions should become an increasing rarity.

Another misperception is the apparent equating of advocacy with militant strategies in the minds of some. In theory, advocacy and militancy are antonyms, not synonyms. Some people conceive of militancy as a recourse when advocacy fails; others believe that advocacy strategies do not fail, that failures are attributable to the inadequacies of people who attempt to practice advocacy strategies.

The closer an advocate gets to the mainstream of decision-making, the greater the awareness of the number of often irrelevant intangibles which impinge upon acceptance of any concept, regardless of its validity. It is said that any idea will be heard and implemented in its time. When that time is, however, is never defined. The advocate must identify what forces are mitigating against the desired results and, if they are a hindrance, seek accommodations before overtly seeking goal achievement. Many self-styled advocates lack the patience or the insight to take this approach, especially since the need with which they are concerned is so immediate. Questions thereby arise over whether anyone faced with the day-to-day inadequacies of a service-delivery system designed to meet all the unique needs of each individual client, can possess the objectivity required in theoretical advocacy. In such instances, is their function of clearly identifying and documenting those needs and issues once again more accurately defined as part of the responsibilities of a service provider?

The intent and need for all that is being done in the name of advocacy is unquestioned here. However, it is being questioned by a public which becomes increasingly and alarmingly more confused. This attempt to raise levels of consciousness, in reality, is a search for a better appreciation of what is done and how it is described to others. Integration of all people with disabilities requires many strategies, utilizes infinite areas of service and employs the expertise of countless specialists. Advocacy plays a minor role in the total constellation. Concepts like "least restrictive environment," "quality of life" and "public awareness," all of which seem more germane to the ultimate achievement of this goal, have been



seemingly underutilized. Can they provide a less confusing framework in which to define needed roles?

Semantic discussions seem fruitless to many people and, in many instances, they well may be. However, when the words used to describe what is being done increasingly seem to block the purposes of such efforts, questions must be raised and clearer definitions sought. Such reviews also serve to clarify and refine processes to achieve desired outcomes. It is from this viewpoint that we must now question "What is advocacy?" and "Who are the advocates?"

### *Implementing A Systems Advocacy Model*

The major thrust of New York State's efforts in the International Year of Disabled Persons was to create a plan for meeting the needs of persons with disabilities in the next decade within the framework and structures of this state's policies and resources. Critical to this undertaking, especially in the light of prior experiences with such global planning, was the need for a strategy to monitor and implement the plan's recommendations. The governor assigned responsibility to develop the plan to a 25-person commission whose membership represented persons with disabilities, parents of such persons, service providers, business, labor, the media and the State Legislature. Technical assistance was provided by the staff of 22 state agencies. In order to facilitate accomplishing of its tremendous assigned task, the commission formed itself into working groups which, for organizational purposes, were grouped around eight cluster topics: advocacy, public awareness, education/vocational/training/employment/job development, independent living, basic research/health care, applied research/technology/adaptive equipment, accountability/standards/documentation, and legislation/administrative regulations. Each of the eight clusters: (1) was chaired or co-chaired by a commission member; (2) called upon the expertise of other New Yorkers in its deliberations; (3) worked from a pre-stated objective written in behavioral terms; and (4) consisted of from three to 10 smaller working groups on diverse issues. For example, the domain of the independent living committee included barrier-free environments, voting

rights, community housing alternatives, the disabled in the aging process, recreation/leisure time activities and respite care.

As previously noted, the commission gave priority to establishing a strategy for monitoring and implementing its eventual recommendations, in preference to in-depth analyses of the sundry issues with which it was confronted. In part, this approach was based on the recognition that the commission's actual lifespan of less than a year did not permit in-depth review of all issues. Further, socio-economic concepts were in a period of nationwide transition, thereby requiring that such review be ongoing for the foreseeable future. As its first recommendation, the commission defined "advocacy," as "the formal role by which any social system -- public, community-based and private -- is made more responsive to all needs of each individual served by that system."

Based upon this definition, a series of recommendations were made concerning the restructuring of the Office of Advocate for the Disabled into a systems advocacy agency which could carry through the tasks commenced by the commission. Included in these recommendations was the concept that the office should be represented on every major policy-making body in state government which is or should be concerned with issues related to persons with disabilities. Governor Carey implemented these recommendations months before publication of the commission's final report.

Consistent with the objective of becoming an effective systems advocate, the reorganized Office of Advocate, which consists of a staff of seventeen, nine of whom are professionals, focused efforts on five areas of concern:

*Community Development* -- Through the implementation of the law permitting counties and certain municipalities to establish councils on the disabled affiliated with their local legislature, five localities within the state, the cities of New York and Buffalo and the counties of Nassau, Suffolk and Westchester, have established offices for the handicapped. These offices, like the Advocate's Office, are part of the government's executive branch. Because relationships between these offices, service providers for all disability groups

which receive local assistance, and the general public have tended to be unclear, it appeared that development of local councils on the disabled affiliated with the local legislative body as authorized by Chapter 638 of the Laws of 1980, would provide a valuable adjunct to office functions. In the rest of the state, such authorized councils were deemed even more essential.

The networking and basic organization required to establish the councils, although significant, is but one part of the technical assistance provided by the Advocate's Office. Ongoing leadership training, both formal and informal, is provided with increasing emphasis on broadening the base of input to the councils. Such consultantships and training sessions also emphasize the strategies of system advocacy in the hope of broadening the perspectives of the sundry interest groups. Proceedings of the formal training sessions are later published, and a variety of other strategies to maintain communication between these councils and the Advocate's Office are operational.

*Legislation* -- The primary priority is establishing communication among the various interest groups and educating such groups in the legislative process; and secondarily, focusing on the identification and passage of significant and needed legislation. In October 1981, the first legislative workshop was attended by representatives of state agencies, statewide provider groups and persons with a variety of disabilities, the majority of whom represented organized consumer groups. More than half of the agenda concentrated on educating the participants about legislative processes, with particular focus on the role of the executive branch of government prior to the onset of the State Legislative session. Again, the prime objective was to effect a networking among the sundry interest groups, rather than to draft specific pieces of legislation.

Not only is 1982 a statewide election year in New York, but there will be a change in executive leadership. It, therefore, became of paramount importance for the Office of Advocate for the Disabled to obtain its legislative base if achievement of the objectives of the International Year of



Disabled Persons Commission was to be realized. This task required passage of a bill establishing a new agency in the first year of introduction of such legislation, a rarity especially in an election year and a time of extreme fiscal crisis. Even before its objective could be undertaken, statewide visibility -- to legislators, service providers, citizens with disabilities, state agencies and other representatives of the general public -- of the office as a valuable resource also had to be created. Achieving visibility within the limited timeframe necessitated, in turn, maintaining a delicate balance between reflecting current trends with realism and maintaining a non-threatening role to the prerogatives of established agencies, both governmental and voluntary.

The evolution of this "broker" role led to real achievements in systems advocacy. The earliest of these was the office's catalytic function in bringing together divergent interests in what has become the New York State Legislative Coalition on Disabilities. While a staff member still attends the coalition meetings as an observer, the office withdrew from any leadership role once this group was firmly established. Interestingly, and partially as an outgrowth of the coalition, a broader statewide federation of concerned agencies, with purposes of public education and political action, is presently under development. The Advocate's Office's role in this is merely one of technical assistance upon request.

As has been oftentimes stated, the absence of a visible power base within the political structure is a major barrier to resolving disability issues. More than any other minority group, all of whom suffer from a lack of visibility at the polls, those concerned with disability issues are not perceived as having meaningful political clout. The office's role in manifesting change must be one of nonpolitical technical assistance. In less than a year, cohesion seems to be developing through such strategies as monitoring the election laws pertaining to accessibility of polling places; training local groups in their responsibilities in the implementation of such laws; encouraging networking with others, perhaps politically more visible groups around common concerns; urging voter registration and enlistment of sundry civic groups to ensure voter partici-

pation; and informing political action groups of the need to include persons with disabilities in their activities and similar activities.

*Job Development* -- With particular emphasis on the private sector, this aspect of systems advocacy is perhaps the most delicate, complex, and yet illustrative of the counterpointing needs of sundry vested interests.

1. The private entrepreneur wants a worker who is qualified to do the job with minimal disruptions to the established organizational patterns and at a cost that is recoverable in profit-making pricing. He perceives that those who approach disability issues from human services aspects are "not living in the real world."
2. The educator and the vocational trainer seem to approach their responsibilities from the abilities and limitations of each client, rather than from the demands of the job market. This approach is further complicated by both the lack of capital funding for re-tooling and concepts of freedom-of-choice. For example, institutions of higher education are still encouraging students with disabilities to enter human services fields, where positions in the labor market have been on the decline for several years.
3. Labor unions, with some cause, perceive workers with disabilities and the sheltered workshops which train them as a threat to union well-being, despite the fact that the original laws governing sheltered employment were drafted with the assistance of organized labor, whose generousities also made possible the construction of many sheltered workshops.
4. The lack of a tangible definition of the concept of "reasonable accommodation" is exacerbated by misperceptions of disabled persons, particularly the severely disabled, concerning individual responsibilities toward obtaining and maintaining employment. Unquestionably, these misperceptions have been fostered by past and present approaches in the education and training of disabled persons, as well as the misperceptions of what constitutes "normal living" as reflected by the media. While this latter phenomenon is not unique to those with disabili-

ties, some avenue of resolution may be more crucial to the survival of persons with disabilities.

Systems advocacy dictates that divergent viewpoints be brought together to identify and resolve common issues. Economic crises are significant threats to polarized interests. Present systems advocacy strategies include involvement with each affected faction in order to create climates and issues where diverse factions are willing to meet and work together. Discrete issues have been developed upon which discussions are occurring among some of the parties. If present trends continue, they may lead to ultimate restructuring of service delivery in line with current and future national needs.

*Information and Referral* -- As an adjunct to systems advocacy, the restructuring of this activity took longer and needed more clarification than any other aspect of the Advocate's Office functions. This is understandable since staff assigned to these functions are constantly in direct contact with individual needs and frustrations. As such, it, therefore, becomes a human imperative to resolve the individual's problems, rather than identifying issues that may, at some later date, be resolved so that the similar problems may not occur. This is best illustrated by the situation where staff established a relationship with personnel from another state agency who expressed unwillingness to be contacted directly by community service agencies. Instead of identifying the person's unwillingness to be contacted, an issue to be resolved at a higher level of management, Advocate's staff acted as an intermediary for the state agencies and provider agencies seeking resolution of individual client problems. Aside from personal reactions to direct contact with individual needs and frustrations, the fine line that must be tread in systems information and referral is often most difficult to distinguish. It is also less personally satisfying to an employee whose generic training has been geared towards the resolution of individual problems. This lack of immediate satisfaction can only be counterbalanced by anticipation that similar individual needs will not exist in the indefinite future.



*Public Awareness and Publication* -- All other areas of concern depend upon and feed into this multi-faceted domain. For example, the four diverse interests identified in the section on job development have a single basic root, i.e., public perceptions and attitudes toward those who have obvious or severe disabilities. Therefore, basic resolutions can only be found if efforts are aimed at overcoming the conscious and unconscious biases towards persons with disabilities which exist in everyone. These biases are more deep-rooted than most presently imagine, and effective techniques in changing present attitudes can result in marked revisions of the service-delivery system. While public service announcements to stimulate change in the average person's attitudes are critical, such strategies will be ineffectual unless there are basic changes in the concepts of disability which are the foundations for decision-making, whether by governmental policy-makers, service providers, disabled persons or self-styled advocates.

A second consideration is the need for information on a level both comprehensible by those needing the information and accessible to the targeted group. An example of this can be found in the numerous publications of the New York State Department of Education and other agencies on rights and processes in the education of all handicapped children. Not only are most of these too complex, both in format and information imparted, for many who need such information, but unless the individual knows where such information can be accessed, the individual needing the information may not even be conscious that he needs it. A systems advocacy agency, therefore, has a responsibility to develop informational materials at appropriate levels and distributing it to generic community groups, even if the only reason for doing so is to advise people of existing rights.

Learning theory reveals that one exposure to information does not necessarily assure that the information is assimilated. In many of this office's activities, it is uncertain whether all or any of those needing information have been present to receive it. Thus, the proceedings of every major workshop, training session or other informational activity

conducted by this office are summarized in a publication. With the political uncertainties surrounding the continuancy of the Advocate's Office, publication of 1981 speeches of the advocate in a bound volume is one strategy for insuring that certain basic concepts are not lost.

A fourth facet of this area of concern is the regularly published periodicals such as the monthly newsletter, "The Advocate," the legislative update, issued during sessions of the State Legislature at a frequency commensurate with legislative activities on bills pertaining to disability issues, and the monthly "Housing Bulletin for the Disabled," which has been a joint effort with the Division of Housing and Community Renewal.

Staff assigned to these responsibilities also provide technical assistance to other agencies and groups in their pursuit of similar objectives. Basic to the concept of systems advocacy is the policy that a priority equal to or greater than that devoted to performance of office advocacy functions should be given to assisting others to perform those activities. A corollary to this premise is that where performance must be undertaken by the advocacy group, it is preferable if other affected entities are co-sponsors.

There are activities which are so speculative that they do not yet fall within the five enumerated areas of concern. These are the special projects, i.e., the ongoing input into various efforts in areas such as transportation, accessibility, prevention and health care. Other office activities are outgrowths of membership in other decision-making bodies, for example the roles played in the Governor's Conference on Prevention of Infant Mortality and Developmental Disabilities, the Governor's Task Force on the Federal Budget or as a part of the overall office responsibilities as an arm of the executive branch of state government. Exercising the "broker" role among legislators and state agencies is a third unclassified type of activity. In all such cases, prerogatives and responsibilities fall to other agencies and input from the Advocate's staff should not be visible.

## Summary

Present conflicts between established concepts and modalities in meeting the needs of persons with disabilities and current national priorities threaten more than two decades of gains. A historic overview indicates that, unlike other social regression in the present political climate, programs and services for persons with disabilities may be markedly reduced, regardless of which political viewpoint holds power, because the public perceives that the delivery system has not contributed to national economic welfare, despite increasing expenditures. To change these beliefs, attitudinal modifications are needed in both the conceptualizations of service providers and the demands of self-appointed spokespersons for disabled persons. The current role of so-called client advocacy must be re-evaluated in light of its true purposes and objectives.

Normalization theory provides the guidepost to what is needed. Advocacy is but one component of that theory; yet, at least in current rhetoric, it has carried the burden of change for betterment, without the benefit of an accepted explanation of what the term "advocacy" means. The New York State Commission on International Year of Disabled Persons attempted to blueprint the modifications and innovations needed to better integrate persons with disabilities into daily community life. In fact, the realities of vested interests, fractionated services, single-purpose goals, public disinterest, fiscal restrictions, lack of political sophistication and conflicting objectives led the commission to evolve a concept of systems advocacy much akin to that conceptualized by normalization theorists.

The basic principles of this model of systems advocacy as a formal part of government and its early efforts at effective implementation are addressed in the belief that this model is replicable at every level of government. Adherence to the precepts of independence from the delivery system, aloofness from party politics and absence of authority beyond the power of verbal persuasion is essential if the model is to succeed. New York State, with its 17 million inhabitants, is a microcosm of national strengths and weak-

nesses. Present and future economic crises, divergent and seemingly insatiable popular demands and polarized perceptions of various interest groups continually place a maximum strain on political processes of state government.

Despite these factors, the state will survive. The government will survive, and the essential needs of its people will be satisfied. It is argued herein that the needs of persons with disabilities can be satisfied with equity only when such needs are considered in the mainstream of decision-making, and not as an add-on to fundamental policies of government. The systems advocacy model, as reflected in the New York State Office of Advocate for the Disabled, provides a vehicle to attain such equality within any democratic political climate.



# **Public Testimony Before Legislative Committees**

\*\*\*Testimony submitted to Senate Committee on Mental Hygiene and Addiction Control, January 12, 1982, Albany

The need for the availability of effective legal advocacy services to individuals who, through circumstances beyond their control, require such services, has long been recognized in this state. The response fashioned -- Mental Health Information Service (MHIS) -- has failed, for a variety of reasons, to address this need in a meaningful manner.

Senate bill No. 6777, introduced by Senator Padavan at the request of the governor, seeks to restructure the existing MHIS as the Mental Hygiene Legal Service (MHLS). In this restructuring, the MHLS would be centralized under the Office of Court Administration. This centralization would, in turn, lead to more uniform provision of quality legal services throughout the state. Far more important, however, the redefinition of the MHLS role -- with the elimination of the prior MHIS obligation to advise the court as well as the client represented -- will enable the MHLS to more closely adhere to the traditional tenets inherent in all lawyer/client relationships.

Approval of this proposal by the legislature will be a major first step in improving the delivery of services to mentally disabled individuals. It is, however, only a first

step. There are issues, both germane to this proposal and going beyond the scope of this proposal, which we must bear in mind as we chart our course for future actions.

First, to assure that the goals of this proposal are realized in implementation, consideration should be given to including consumer/patient/client representatives on the MHLS board; clarifying the relationship between the MHLS and the Commission on Quality of Care for the Mentally Disabled's protection and advocacy system unit; and assuring that appropriate staffing divisions are drawn, where necessary, to protect the interests of developmental center clients when they are in conflict with the interests of psychiatric center patients, and vice versa.

Beyond the scope of this particular proposal, there is a broader issue which must be posed. Consideration must be given to generally expanding the availability of legal advocacy services to all persons with disabilities, physical as well as mental, who need such services because of their disability. Equality of services for all persons with disabilities has long been a goal of my office, and many people with a physical disability have as great a need for legal advocacy services as do those for whom the MHLS is designed to serve.

Senator Padavan, I appreciate having been given the opportunity to address your committee today. It is my sincere hope that your efforts will result in the enactment of Senate 6777, and that the careful implementation of the reforms which will ensue will improve significantly the quality of legal advocacy services to individuals receiving mental hygiene services from the State of New York.

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\*\*\*Testimony submitted to Assembly Standing Committee on Real Property Taxation, January 25, 1982, Albany

I appreciate the opportunity to address this joint hearing today on the subject of real property tax relief for persons with disabilities.

Initially, I would stress that it has consistently been the position of the Advocate's Office that persons who are disabled should not, solely on the basis of their disability, be entitled to special privileges or government gifts not available to the general population. Rather, our efforts should be targeted to assuring that persons with disabilities are afforded the opportunity to become fully participating citizens in the activities of community life.

With that introduction, let us turn specifically to the issue of real property tax relief.

Based upon the nature of the inquiries to which the information and referral service operated by the Advocate's Office responds, it has become apparent that employment, transportation and housing are the three most critical issues which persons with disabilities must face. While the availability of adequate and affordable housing is a problem faced by all segments of our population, the situation is compounded for persons with disabilities because of the limited availability of accessible housing.

There are several options which might be pursued to use the Real Property Tax Laws to promote the availability of accessible housing. First, property owners, whether or not they themselves are disabled, should be insulated from any increase in the assessed valuation of real property, when such increase is based upon reasonable structural modifications undertaken to increase accessibility or adaptability. Second, the feasibility of tax incentives to encourage property owners to undertake such structural modifications should be explored. Third, any general real property tax relief program for persons with disabilities, whether structured as an exemption or deferral, must be available to all persons with disabilities and must include eligibility criteria which is based on a realistic evaluation of need demonstrably related to the disability. In short, direct tax relief should be afforded on the basis of need for such relief, and not solely on the basis of disability.

In any effort to structure a program of real property tax relief to benefit persons with disabilities, there are three additional and vital considerations which must be kept in

view. The projected benefits of affording persons with disabilities increased opportunities to live in the community and to partake, on an equal footing, of the activities of community life are evident in the human dignity and sense of independence which community living fosters. In addition, real cost savings may accrue to the state where tax relief is designed to enable an individual with a disability to live in his or her home rather than the alternative which may be a more costly institutional placement. Finally, any loss in revenue which results from tax exemptions or deferrals may well be offset by income tax or other revenues which may be generated when real property tax relief permits an individual to make structural modifications to his or her home which will facilitate outside employment or permit an individual to live at home and work at a job in the community. These benefits will, however, be realized only where adequate community support systems are in place. The availability of home-health, social and other habilitative services in the community are a vital adjunct to any comprehensive program designed to afford persons with disabilities the opportunity to live and work in their chosen communities. (Editor's note: Chapter 200 of the Laws of 1983 now authorizes localities to adopt real property tax exemptions for improvements to certain real property for the purpose of accommodating the owner who has a physical disability or a member of the household who has a physical disability).

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\*\*\*Testimony submitted to the Assembly Standing Committees on Health and Aging, January 29, 1982, Albany

According to data recently compiled by the New York State Health Planning Commission, the percentage of New York State's population in the over-65 age group is projected to increase by at least 16 percent in the period from 1970 to 1990. While it must be understood that not all persons over the age of 65 require some mode of service from the long-term-care services continuum, it must be



recognized that individuals who have the greatest need for such services are those in the over-75 age group. The projection that by 1990 there will be an additional 93,000 New York residents over the age of 75, coupled with the fact that eight percent of the current population age 75 and over reside in residential health care facilities, clearly indicates the continuing and growing need to assure the availability of appropriate long-term-care services.

In discussing long term care however, it is important that we not limit our consideration to accommodation for the elderly. Other individuals with physical or mental disabilities, many of whom are not in the age-65 group, are also in need of the specialized services which are provided through the continuum of long-term-care services.

Given these two factors, the increasing size of the long-term-care target population, and the recognition that long-term-care services are provided to individuals with disabilities who may or may not be members of the traditional target population, there are several important considerations which we must bear in mind as we begin to design the structure of a long-term-care system for the next decade.

First, as you are well aware, the time to plan is now. If New York is, in fact, to design a workable system rather than merely react to a system which has developed in a reactionary fashion, we must begin now to select and pursue viable strategies.

Second, we must assure that services are provided which are appropriate to all individuals who require long-term-care services. That is, program design must first take into account the client mix and then structure programs which are beneficial to both the frail elderly person and the person with a disability. In the same vein, the importance of integrating services for persons with disabilities throughout the continuum of services is readily apparent; for too long persons with disabilities who require long-term-care services have been isolated from the rest of the long-term-care target population. Such isolation has had debilitating effects both on the individuals so isolated and on others re-

ceiving long-term-care services who might benefit from the types of habilitative services provided to persons with disabilities. Substantial medical advances over the past few years have resulted in a markedly increased lifespan for persons with disabilities. In order to assure that appropriate services to the elderly person with a disability are integrated into the system, we must promote research which will define what types of services are most needed, and then devise strategies to see that the identified needs are addressed.

Third, increased emphasis must be placed on the development of noninstitutional community-based support systems. The provision of home care, social, habilitative and other services which may forestall or prevent more costly institutional placement has clear rewards, not only in terms of dollar savings, but also in terms of the heightened sense of dignity and independence which may be fostered in an individual who is able to remain in his or her own home. A vital, but often overlooked adjunct to the provision of such services is the development and promotion of accessible and adaptable housing for both persons with disabilities and the elderly, who often benefit from many of the same modifications commonly made to accommodate persons with disabilities. Increasing at-home services can be of only limited utility unless the housing itself is designed in such a way as to facilitate the performance of the activities of daily living.

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\*\*\*Testimony submitted to the Legislative Commission on Critical Transportation Issues and the New York State Senate Committee on Transportation, February 22, 1982 Albany

As you may already know, a recent State Supreme Court decision granted an injunction which halted renovation projects in 10 New York City subway stations because planned renovations did not include provisions mandated

by the State Public Buildings Law for improving accessibility for persons with disabilities. At the same time, lift-equipped busses -- the utility and operability of which are questionable -- have been put into operation in New York City to satisfy federal requirements that special efforts be undertaken to improve the accessibility of the city's mass transportation for the disabled. I have commenced my presentation with these two examples to highlight what I feel to be the most critical transportation issue with regard to persons with disabilities, the absence of a clearly enunciated state policy to integrate planning for accessibility improvement into the general transportation planning process.

Along with the availability of accessible housing and the opportunity for meaningful employment, the availability of accessible and affordable mass transportation ranks among the most frequently cited needs of persons with disabilities throughout this state. While employment has consistently been considered the key to the complete integration of persons with disabilities into their chosen communities, it has become increasingly obvious that the availability of accessible and affordable mass transportation is, in many instances, essential if persons with disabilities are to take advantage of employment opportunities. Parenthetically, it should be noted that all population projections estimate that by the 1990's there will be a shortage of workers from traditional sources to meet the then-current labor market needs. This means that elderly and disabled persons will be among the populations which we must tap in order to maintain our economy within the next decade.

The 1973 Statewide Master Plan for Transportation does note, under a heading of "Policy Changes," that developers of public transportation must consider and, to the extent feasible, accommodate the needs of the physically handicapped and infirm in the design and development of transportation facilities and services. Since the 1973 plan was developed, a complicated network of state and federal regulations regarding accessibility of individu-

als who are mobility-impaired has evolved. While my purpose today is not to enumerate those regulations, I would note that the state has imposed requirements under the Public Buildings Law and the State Building Code and that the federal government has also set mandates, including the much-debated nondiscrimination and "special efforts" requirements promulgated in regulations pursuant to Section 504 of the Rehabilitation Act of 1973 and the Uniform Mass Transit Act of 1964. This confusing and sometimes duplicative network has, in many instances, served as an excuse for noncompliance or feigned or real ignorance regarding accessibility requirements. This confusion is further exacerbated by failure to clearly differentiate between what is policy and what is affordable at any given time. To me, these are two separate questions; first comes a policy statement and then comes a plan to mold that policy statement to what is or can be affordable at any given time period within the structure of the total plan.

The policy change recommended in the 1973 plan has been reiterated in greater detail by the New York State Commission on International Year of Disabled Persons, which was chaired by Governor Cuomo. In its final report, the commission included seven specific recommendations regarding the improvement of public transportation services for persons with disabilities. Those recommendations ranged from increased emphasis on enforcing accessibility standards to developing interstate reciprocity arrangements to recognize handicapped parking permits. In addition, the deliberations of the Advocate's Office 1982 Legislative Workshop resulted in four specific recommendations which emphasized the importance of developing local transportation planning processes.

#### *International Year of Disabled Persons Recommendations*

1. The state Department of Transportation should take a lead role to ensure the enforcement of accessibility standards regarding both transportation vehicles and



facilities, particularly to ensure full utilization of recently purchased, lift-equipped buses and that newly built, as well as remodeled facilities, are fully accessible;

2. The governor should create an interagency task force to develop proposals to coordinate the transportation services of local service providers. Member agencies should include: departments of Transportation, Education (Office of Vocational Rehabilitation), Social Services (Commission for the Blind and Visually Handicapped), offices of Mental Retardation/Developmental Disabilities, Mental Health, Aging, Division for Youth and Office of Advocate for the Disabled. The task force should be chaired by the Advocate for the Disabled and make its recommendations to the governor within 12 to 18 months of its creation;
3. The state Department of Transportation should evaluate the utilization of lift-equipped buses to determine design adequacy, route planning, scheduling, public awareness and need. Consultation should be made with persons with disabilities in conducting this evaluation;
4. The Office of Advocate for the Disabled should develop legislation to provide a tax benefit for persons with disabilities who, of necessity, incur higher-than-normal transportation expenses in commuting to work because of the insufficiency of adequate, accessible public transportation;
5. Because of the inadequacy of accessible public transportation and the subsequent need or preference for many persons with disabilities to rely on private transportation, the Office of Advocate for the Disabled should develop legislation leading to the uniform provision of on-street special parking for qualified holders of the New York State handicapped parking permit or disabled driver registration plates;
6. Similarly, the Office of Advocate for the Disabled should work with contiguous states to develop recipro-

- city agreements regarding vehicle identification and special parking; and
7. The state Insurance Department, through legislation or regulations, should mandate that automobile insurance fees for persons with disabilities be based on actuarially determined driving records.

### *1982 Legislative Workshop Recommendations*

1. The development of local transportation planning processes, responsible for the design of accessible, affordable and reliable transportation, should be mandated with the requirement that persons with disabilities participate, in decision-making capacities, with local elected officials and transit personnel in creating the mechanisms;
2. A study should be required to develop safety standards for lift equipment. It should be obligatory that persons with disabilities participate with transit-system operational and maintenance personnel in its undertaking;
3. Localities should be mandated to have a local transportation coordinator responsible for maximizing the availability and usability of existing transportation services for persons with disabilities; and
4. Increased emphasis should be placed on enforcing accessibility requirements under Public Buildings, Civil and Human Rights Laws.

As a basis for the comprehensive implementation of any specific recommendations, however, it is critical that future iterations of the statewide Master Plan for Transportation include clear policy and direction statements that commit the state to seeking out and implementing realistic and affordable resolutions of mass-transportation-accessibility issues. Such policy and direction should include provisions to involve persons with disabilities in all stages of the planning and development of transportation facilities, and services must be sufficiently flexible to promote the development of local resolutions to local pro-

blems. Above all, it must be recognized that accessibility issues must be integrated into all phases of project planning and development

The benefits which can result from the practical and affordable implementation of such a policy accrue not only to persons with permanent physical disabilities, but also to the elderly, the businessman or woman with a cardiac condition, the young parent with a child in a stroller or any other person whose mobility may be permanently or temporarily impaired. More important, the state, its taxpayers and its industries can realize a significant fiscal advantage because improved accessibility can permit individuals who have previously been unable to work outside the home to enter the mainstream of the workforce, move from economic dependence to independence and contribute, as wage-earners and taxpayers, to the general welfare of all citizens.

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\*\*\*Testimony submitted to the Subcommittee on Health Insurance, The Council on Health Care Financing, February 25, 1982, Albany

Although I know that the topic is health insurance in New York State, I would like to start by suggesting that we refocus our basic concept of health care from a sickness model to a wellness model.

It is accepted wisdom, by this time, that significant advances in well-being will no longer come from the type of public health activities we have become familiar with over the last 100 years. Individual behavioral change is now needed. We eat too much, we drink too much, we smoke too much, we drive too fast. As we build supports for people to change their lifestyles, we may expect a healthier population. Both the corporate sector and, I am happy to say, New York State government are looking at health promotion and at motivating employees to better health. I would like to suggest that there may be incentives

in the way health insurance is structured that can encourage the development and advancement of wellness programs.

We would like to stress prevention, education and the development of effective community support systems as mechanisms to reduce growing health-care costs. Governor Carey in his annual Health and Human Services Message stated that he is proposing legislation requiring that new health insurance policies provide the option of preventive care in the first 12 months of life. We support this, as well as the legislation that was passed last year requiring infant car seats, and we continue to support the requirement of helmets for motorcycle users. Campaigns that bring before the public prevention concerns such as Fetal Alcohol Syndrome, immunization, prevention of unwanted adolescent pregnancy and promote increased reliance on the formal and informal support networks available in the community must be supported both to provide better health care now and to prevent greater health costs in the future.

With the foregoing as background, I would like to share with you some specific concerns with regard to the current structure of health insurance programs.

When a person has to stop working because of a disability, that person, if eligible for Social Security disability benefits, has to wait two years after benefits begin for Medicare coverage to commence. While some companies continue to pay for a terminated employee's health insurance policy through their group plan, many disabled workers are faced with having to pay for an individual converted policy which is much more costly, at a time when their overall resources are shrinking rapidly due to loss of wages and increased medical costs. In either case, two years after Social Security disability benefits begin the individual becomes eligible for Medicare.

At that point, while most policies convert to a Medicare supplementary coverage, these policies only provide payment of medical expenses up to what Medicare considers reasonable charges; and so disabled people are often left with less insurance than they had while they were still



working and had fewer medical bills. At this time, they also frequently lose the prescription drug coverage which they had while working. Senate bill 4847, 7685 in the Assembly, would address this problem by providing that when an individual qualifies for Medicare coverage, he could obtain a Medicare supplemental policy to replace coverage formerly provided under the converted policy.

Disabled people who do not qualify for Medicaid or Medicare have great difficulty obtaining medical insurance. Private carriers are extremely reluctant to issue individual policies. Our office has advised people to join organizations -- where they exist -- which have group policies that cannot exclude a member of the group. People should not have to resort to this circuitous route in order to obtain insurance coverage.

The state should encourage the provision of catastrophic illness or disability coverage. At a time when the maintenance of a strong family unit is so essential, adequate catastrophic insurance can avert the tragedy of a family breaking up just to qualify the disabled person for Medicaid. This is particularly true when a catastrophic incident necessitates long-term care. Spouses are often faced with a dilemma of having to divorce their mates in order for the disabled person to qualify for home-health care or long-term hospitalization.

Medical insurance policies, including Medicare, do not as a rule cover the costs of transportation to and from medical appointments even when ambulettes or taxis are needed. At a time when very limited public transportation is accessible, the high cost of private transportation often prohibits those unable to use the public system from obtaining adequate medical care.

Long-term care has become an increasing concern of the state as more and more Medicaid dollars flow into nursing homes. Through the State Health Planning Commission, a process has been started to plan for the continuum of long-term-care needs of disabled and frail-elderly individuals. I would suggest that consideration be given to funding a few model programs which would address the comprehen-

sive needs of individuals -- particularly those who are above Medicaid limits -- to prevent institutionalization.

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\*\*\*Testimony submitted to the Senate Standing Committee on Government Operations and the Assembly Subcommittee on Human Rights, March 9, 1982, Albany

The Division of Human Rights performs an invaluable service for citizens with disabilities in New York State. As the state agency with the primary responsibility to enforce those provisions of the Human Rights Law which prohibit discrimination on the basis of disability, the division has provided the technical expertise and manpower which is required to assure that persons with disabilities are not subjected to unlawful discriminatory practices in such areas as housing, employment and transportation.

It is indeed unfortunate, in this day and age, that preventing the perpetuation of unlawful discriminatory practices is so herculean a task. Notwithstanding the efforts to date of the governor and the legislature, there remains a great deal to be done if citizens with disabilities are to be afforded the opportunity to become full participants in the activities of their chosen communities.

For example, close to two decades of effort have yet to result in a statutory guarantee of civil rights for persons with disabilities. There are currently a number of civil rights proposals pending in the legislature, including a Governor's Program Bill, S. 4909-A/A. 7319, the enactment of which is a necessary prelude to further opportunities for the advancement of persons with disabilities.

Because of the magnitude of the task which remains, I would like to briefly suggest some of the ways in which my office may be of assistance to the Division of Human Rights in their efforts to enforce provisions of the Human Rights Law prohibiting discrimination on the basis of disability.

First, I would like to make it very clear that my office does not provide direct legal representation for individuals seeking to redress a violation of the provisions of the Human Rights or other state or federal laws prohibiting discrimination on the basis of disability. We are, first and foremost, systems advocates and not an avenue for private representation. When we are contacted by an individual who wishes to pursue such violations, we routinely refer that individual to the Division of Human Rights or other appropriate state or federal law enforcement agency. Many of our contacts, however, are from individuals or groups who are merely seeking information regarding rights, responsibilities or the availability of services. In such cases, we may provide the information requested directly, or make a referral to the appropriate service-provider agency. In many cases, the ready availability of such information -- whether the inquiry be from an employer seeking information regarding accommodations for employees with disabilities or from a citizen with a disability seeking information regarding the statewide handicapped parking permit -- may prevent a situation from arising in which litigation becomes the only means of addressing a real or perceived violation of state or federal nondiscrimination provisions.

Because of the scope of their mandate, practical considerations preclude the division from providing this type of specialized information and referral service for persons with disabilities, and require that primary attention be focused on the pursuit of legal actions filed under the Human Rights Law.

An increased emphasis on cooperative efforts between the division and my office will work to the mutual benefit of both entities and for the benefit of the individuals each entity services. For example, when the division refers requests for information to the Advocate's Office, my staff may be able to provide the type of information or technical assistance which obviates the need for litigation, which, in turn, may help to reduce the case backlog in the division and enhance the ability of the division to provide appropriate representation in a timely fashion.

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\*\*\*Testimony submitted to the Assembly Task Force on the Disabled and the Senate Select Committee on the Disabled, March 23, 1982, Albany

Last year I submitted testimony on guaranteed, minimum wage legislation to the Assembly's Special Task Force on the Disabled. In the interim months, my staff, committees of the New York State Commission on International Year of Disabled Persons and I have researched this issue in depth. Our findings were substantiated in the reports of two research studies done by independent bodies to which I will refer later. It is of interest to note here that the General Accounting Office's (GAO) study was initiated by Senator Barry Goldwater, who, in requesting the study, implied that he supported federal legislation similar to what is being considered here today.

Our year of research has convinced us that this bill is only the tip of the iceberg, the complexities of which must be carefully reviewed before any action is taken. For example, the very term "minimum wage" is ambiguous as it pertains to existing legislation on sheltered workshops and labor laws. Minimum wage is often used interchangeably to refer to three significantly divergent concepts; statutory minimum wage, prevailing industrial wage and arbitrary minimum wage.

- (a) The statutory minimum wage (currently \$3.35 per hour) is the minimum wage mandated to be paid to employees by the Federal Fair Labor Standards Act of 1938, as amended. The act, however, includes several exceptions to this mandate under which employees may be paid less. Disabled workers in sheltered workshops are to be paid wages commensurate to those earned by nondisabled workers in the same geographic area for similar work, but not less than 50 percent of the statutory minimum wage. A wage of 50 percent of the statutory minimum wage, currently \$1.67 per hour, is referred to as the "sub-minimum wage." Further exceptions provide for the



issuance of special certificates for the employment of disabled individuals in sheltered workshops at less than 50 percent of the statutory minimum wage where (1) employment is incidental to a training/evaluation program; (2) employee earning capacity is so severely impaired that competitive employment is unlikely; or (3) the employee is working at a work-activity center. In such cases, wages must be related to worker productivity, even where productivity may be inconsequential.

- (b) Prevailing industrial wage is that wage which is paid to nondisabled workers employed in the same geographical area and doing the same type, quality and quantity of work.
- (c) The arbitrary minimum wage is a minimum wage set at an arbitrary level, unrelated to geography or productivity.

If this breakdown seems confusing, I would caution that there are almost infinite subcategories and permutations of this basic breakdown of requirements affecting wages paid to workers with disabilities. To understand these complexities often seems rather like waltzing with an octopus. This semantic confusion is only a prelude to the complexities of the issues which follow. Let us presume for the moment that the current bill refers to the statutory minimum wage.

As those of you who have heard me address this topic before are well aware, I am firmly convinced that we cannot allow our dialogue to be limited to considering only protected employees who are blind. While citizens who are blind and their advocates have been most effective in bringing minimum wage issues before the legislature, the issues so raised are neither unique nor exclusive to blind workshops. The focus of my efforts over the past year, and the focus which I urge you to adopt, has been to attempt to assure, in an era of rapidly decreasing resources, that services for persons with all types of disabilities are not disproportionately reduced. A key element of any such assurance must necessarily be the recognition that we can no longer afford the luxury of targeting our efforts to the

provision of special or unique services to special disability groups. Rather, we must make every effort to assure that basic, essential services are available to all persons with disabilities. To that end, our efforts -- with regard to issues affecting sheltered workshops -- must be directed at improving employment opportunities for all sheltered workshop employees, not only those who are blind.

Because you will be offered a variety of positions today on the positive and negative impact of specific proposals to guarantee a minimum wage to individuals employed in a sheltered employment setting, I would prefer to take this time to suggest a course which your deliberations might follow that will result in a reasoned and equitable response to concerns which proponents and opponents of the minimum wage guarantee will raise.

As an initial step, I would recommend a careful, in-depth review of two recent studies on sheltered employment. The first is the GAO study which reviewed the role of sheltered workshops in the employment of those with physical and mental disabilities and the operation of such workshops in the competitive business community. More specifically, Senator Goldwater's request was submitted in response to concerns raised with regard to minimum-wage mandates. The second study, conducted by Monroe Berkowitz of Rutgers College, is targeted specifically to the issue of wages in sheltered workshops.

In addition to these key studies there have been other important developments which I would bring to your attention.

1. The Management Systems Unit of the Division of the Budget (DOB) has included an analysis of the wages paid in sheltered workshops in their overall study of sheltered-workshop operations. This significant report has, however, yet to be published. I would urge that this report be reviewed as soon as it is available, and that the legislature avail itself of the DOB analysis.
2. Similarly, the Office of Mental Retardation/Developmental Disabilities Fee for Service Council is in the process of developing a report to the legislature on the crea-

tion of an equitable and affordable mechanism to fund day-training programs. To rationally fulfill their legislative mandate, members of the council have found it necessary to re-examine the entire continuum of services to post-school-aged adults with disabilities in order to clearly identify the domain of day training. It is essential that the findings of the council be reviewed prior to final legislative action to assure that any statutory response can be coordinated with other components of the overall continuum of services for persons with disabilities.

3. Another factor which must be considered is the extent to which federal statutory and regulatory changes may affect services to sheltered-workshop clients. You will recall that in my testimony before the Assembly Task Force last year, I questioned the impact of minimum-wage guarantees on the future availability of sheltered-employment services to the majority of workshop employees who are currently paid less than the statutory minimum wage, as well as the impact on those limited numbers of employees currently receiving the statutory minimum wage. Because the Social Security Administration has not yet made information available about how changes in benefit and eligibility levels under programs such as Supplemental Security Income, Social Security Disability Insurance and food stamps will effect sheltered-workshop client benefits and income, it is still impossible, at this time, to determine the effect that a minimum wage guarantee will have on an individual's ability to provide for basic life-sustaining necessities.

Thus far I have outlined a number of factors which should be considered. Now I would like to suggest that you not limit your deliberations to considering alternatives which are, in my estimation, Band-Aids, and not cures or resolutions to the problems which sheltered workshops currently face.

I am suggesting that complete review of the purposes and functions of sheltered workshops is long overdue, and that consideration should be given to developing a new sys-



tem which is based on new concepts. To date, New York State has not adopted a policy statement supporting the development of such new approaches, let alone promoted a mechanism by which they can be developed.

In existing agencies today -- and for good and valid clinical reasons -- three distinct modes function side-by-side in the service continuum, indistinguishable to the casual observer. They are vocational training, and, what I will call for want of better terminology, the two aspects of modified employment -- sheltered employment and sheltered industry. Under a restructured system, workshops would be organized along the lines of either of two models. The first, sheltered employment, as used here, would provide employment to persons whose productivity is markedly below any minimum standard and who are otherwise unable to cope with competitive placement. Such employment may also be used as a long-range strategy to enable the individuals to benefit from vocational training and other services in the future. In such a setting, workers would continue to be paid at a rate based on standard minimum wage as pro-rated according to their productivity levels. However, the concept of the arbitrary minimum wage for those with disabilities who are qualified for less than 50 percent of the statutory minimum wage in certified workshops, as it exists in the early stages of the vocational training continuum, may be considered for incorporation as a legislatively established baseline (for example, "no worker in sheltered employment shall be paid less than fifty cents per hour"). It must be pointed out, however, that any such legislation would not resolve the need to monitor current practices in wage computations, as was noted in my testimony of last year.

When an individual's productivity reaches competitive levels, that person would become eligible for competitive placement or placement in the second mode of operation. The second model, sheltered industry, would be geared to individuals who, for a variety of reasons, cannot cope with the milieu of the competitive working environment, yet have rates of productivity which equal or exceed those



of a nondisabled worker performing the same function. A sheltered industry would employ only workers whose productivity warrants earnings at statutory minimum wage or the prevailing industrial wage, whichever is higher. Center Industries of Wichita, Kansas, is an outstanding example of such a sheltered industry.

In developing such models, several components should be considered for inclusion:

- (1) Client advisory boards should be key elements in the operation of either model.
- (2) The International Year of Disabled Persons Subcommittee on Employment stressed the necessity of involving representatives of both labor unions and the business community in the development and operation of sheltered-workshop programs in order to assure that skill training is truly responsive to the manpower needs of the competitive labor market. Involvement of such representatives can also assure that other issues, like the arbitrary minimum-wage concept, will receive similar review.
- (3) As employee productivity increases to merit payment of the statutory minimum wage or a higher prevailing industrial wage, such employees should be afforded those benefits customarily afforded to other nondisabled employees in similar industries, and in turn, should be required to make at least partial payment for other related services which may be provided incidental to employment, such as counseling, transportation and medical care.

The final observation is that during the past year I have learned that the impetus for this bill stems in part from a perception that nondisabled workers in workshops for the blind earn minimum wage or higher, while those who are blind -- and are equally, if not more productive -- do not. As you know, perceptions cannot always be rectified by factual arrays. The Javitts-Wagner-O'Day Act provides that up to 25 percent of the hours worked in workshops for persons who are blind may be performed by sighted persons. This provision has always been interpreted in practice

as authorizing employment of persons who have no disability. New York State can set an example for the rest of the nation by passing legislation requiring that, within its jurisdiction, at least a majority of such sighted employees have other disabilities.

I thank you for the opportunity to address the Joint Committee. While I have not provided you with answers to the difficult questions which you must face, I have tried to suggest a direction which you might pursue in seeking those answers. Please do not hesitate to call upon my office for assistance. And, above all, I ask you not to respond in haste to pressures for immediate action. Review all the factors which affect the issue carefully, and do not permit the response which you fashion to be limited by the parameters of the existing sheltered-workshop structure.

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\*\*\*Testimony submitted to the Assembly Subcommittee on Human Rights and the Assembly Task Force on the Disabled, November 15, 1982, New York City

As you know, the Advocate's Office recently published and distributed the final report of the New York State Commission on International Year of Disabled Persons. This report is the culmination of an eighteen-month effort to design a blueprint for realistic, effective and affordable state initiatives to promote the complete integration of persons with disabilities into their chosen communities. I would like to take a few moments to review with you several of the commission's recommendations as they pertain to the aging-out dilemma.

However, before I begin on the specific recommendations, your attention is called to Chapter 544 of the Laws of 1982 which established a mechanism to provide appropriate planning for in-state services for students currently in out-of-state educational placements who reach the age of 21 and require adult services. This new law represents a significant first step in promoting the continuum-of-ser-

vices concept. It is important that we realize, however, that Chapter 544 is only the first step. Serious consideration must now be given to the creation of a parallel planning process for individuals reaching age 21 who are already receiving services in-state. As in Chapter 544 of the Laws of 1982, we urge that the assignment of responsibility for the development of such a mechanism be given to the Council on Children and Families, as this council consists of a legislatively based consortium of the many agencies concerned with issues related to persons with disabilities, their families and their advocates.

In its deliberations the commission was concerned that services which are currently provided to persons with disabilities may not meet the current and future needs of persons with disabilities, particularly those with severe, profound and/or multiple developmental disabilities. It examined and made recommendations concerning such issues as:

1. The need to more accurately ascertain the numbers of New Yorkers requiring services, particularly those requiring adult services;
2. The nature of the services required, specifically those services which will lead to more complete integration of persons with disabilities as productive members of their home community;
3. The need to re-evaluate the quality of programs and services now being offered children with developmental disabilities because such services are prerequisites for adult productivity;
4. The need to question the assumption that persons with severe and profound multiple disabilities are continually classified as a permanently dependent population;
5. The need to implement the recommendations of the 1981 Governor's Conference on Prevention of Infant Mortality and Developmental Disabilities in combination with the commission's recommendation on early childhood intervention, to prevent continuation of the aging-out dilemma in perpetuity;

6. The need to promote the development of modern technology in New York State and utilization of that technology to better prepare the person with disabilities to assume the responsibilities of citizenship; and finally,
7. The need to integrate issues related to persons with disabilities into the mainstream of this state's decision making so that needed programs and services will not only be affordable in times of economic crisis, but will become so much a part of the economy of the state that their continuation will be insulated from future threats of elimination.

This state has faced more than its share of crises in the last several years. Fiscal shortfalls, the threat of municipal bankruptcy and the avalanche of human misery triggered by Reaganomics have all been faced and, in some fashion, addressed by the state. We are now faced with an additional economic crisis which perhaps is more insidious than any we have known before. The level of aspiration of New Yorkers looking to their state government to resolve human needs is greater today than ever in history. The current transitional dilemma for disabled 21-year-old individuals in need of adult services is one which must be viewed within the totality of this state's needs and priorities. We must begin by doing three things. First, we must create a mechanism to assure appropriate planning for adult services which will parallel Chapter 544 of the Laws of 1982. Second, we must assure that any resultant programs and services instituted in response to identified needs are guaranteed continuation in a cost-effective manner. Third, any planning process instituted must simultaneously interface with the implementation of the other recommendations of the Commission on International Year of Disabled Persons (Editor's note: Chapter 570 of the Laws of 1983 creates the appropriate mechanism for planning recommended).



## Education

\*\*\*Testimony presented before the Federal Department of Education, September 16, 1982, New York City

At the 1982 annual meeting of the President's Committee on Employment of the Handicapped (PCEH), the 40 states represented unanimously passed a resolution, which was later delivered directly to the White House, expressing the committee's concern that revisions of regulations under P.L. 94-142 and Section 504 not inflict irreparable harm on potentially productive citizens. It is in the spirit of this resolution, prepared by New York and the seven other Northeast member states of PCEH, that I address you today.

New York State is indeed fortunate in having had the type of leadership which recognized the importance of codifying certain procedures and protections for the education of children with handicapping conditions in its Education Law and in Part 200 of the Commissioner's Regulations. As such, the proposed revisions to the federal regulations, if enacted, would probably have minimal immediate impact on New York. I have, however, two concerns which carry beyond the boundaries of this state.

First, certain provisions in the proposed regulations may have an adverse impact upon the future level and quality of services available to children with handicapping conditions in New York, as well as upon implementation in other states. While I will outline my specific concerns and objections in my formal comments to the secretary, the thrust of my comments will emphasize the notion that the federal government must not abdicate its responsibility, particularly in this

era of growing fiscal constraint, to guarantee to all children with handicapping conditions a minimally acceptable level of educational services. While increased flexibility for the states is desirable in many instances, the federal government must continue to impose certain responsibilities and demand a certain level of accountability in its dealings with the states.

My second concern is that we, as advocates, do not allow preconceived notions to color our review of these regulations. While the hallmark of the Reagan Administration has been its unprecedented assault on this nation's most vulnerable citizens, we must maintain our objectivity and evaluate each proposal on its own merit. P.L. 94-142 and its current regulations were born out of compromise and the need for revision has been clear for several years. Such a revision must, however, occur only after thoughtful deliberation on the advantages and disadvantages of each individual proposal.

Some fundamental questions underly both of these concerns. Is the law and its regulations fulfilling its original intent? Complaints about program costs seem merely to reflect dissatisfaction about results among those who are not sufficiently informed to pinpoint the roots of their dissatisfaction. The single greatest achievement of P.L. 94-142 is that children with severe and profound disabilities are now receiving an education, which is their right as expressed in national policy for over a century and repeatedly reaffirmed by every presidential administration in this century. But what about the quality of that education? Is it preparing the student to be a productive community member or are existing attitudinal biases perpetuated in education programs which reinforce a lifetime of dependency. If the latter, should not these issues be the focus of present concerns? We, as a nation, cannot continue to support 35 million people as a dependent population, especially when such dependency is unnecessary and, in most cases, caused by what we do in the name of humaneness.

In speaking of attitudinal biases, I cannot resist commenting on complaints about parental participation in the individualized educational program (IEP) process and existing challenges to present concepts of support services.

Change is inevitable in all things. To take a position that does not tolerate change is both unrealistic and short-sighted. New York State's Commission on International Year of Disabled Persons recognized the need to review and revise a number of current practices affecting the education of children with handicapping conditions. We have made recommendations regarding planning, curriculum, staff development, support and related services. It is this type of effort, in conjunction with a careful evaluation of the proposed regulations, which will help to assure that changes in P.L. 94-142 regulations can be constructively effected in a manner that will further the initial objectives of Congress to afford needed flexibility to the states and to improve both the education and quality of life for all of this nation's children with handicapping conditions.

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\*\*\*Testimony submitted to Senate Standing Committee on Higher Education, September 24, 1982, Albany

I would like to direct my comments specifically to the need for us to review the nature and quality of the training which our educational system is currently providing to citizens with disabilities and to revise curricula to more appropriately reflect the changing needs of employers in today's job market.

For many disabled persons, the key to successful integration into the activities of community life is the ability to obtain employment in positions for which they are qualified. To provide disabled persons with an education that does not include the attainment and maintenance of a marketable skill is a great disservice because levels of aspiration are raised without equipping the individual with the necessary tools to realize those aspirations. I think of a friend of years-gone-by who earned a Ph.D in psychology, cum laude, from Columbia University, but could never find a job because of his inability to speak intelligibly, to write or type, or in some other fashion demonstrate the marketability of his hard-won skills.

In the late 1960's and throughout the decade of the 70's, the field of human services seemed to hold great potential for employment. Many colleges and universities developed degrees in human service in response to labor-market demand for the types of general skills which were adaptable to human service programs. Reaganomics and the resulting demise of many such human service programs has put a swift end to the demand for generalists. At the same time, many of our vocationally oriented programs continue to train individuals exclusively for a service-oriented economy which has been, and continues to be, increasingly displaced by the demands of high-technology oriented programs.

As a result of the Vocational Rehabilitation Act of 1973, as amended, and particularly Article 5 thereof, all state colleges and universities and many private colleges added coordinators for disabled students to the staffs. However, the majority of such coordinators in this state report that they have minimal or no contact with administrative and academic advisors. This, combined with a skewed interpretation of personal freedom of choice, allows and even encourages students with disabilities to pursue studies leading to unrealistic aspirations. While no one advocates limiting the individual's freedom to choose, intelligent choice is contingent upon adequate information and guidance, particularly as it relates to the nature of the world of work.

There are several questions which we must ask of our educational systems. Are we preparing students with disabilities for real life experiences, acknowledging in our curricula that biases exist toward disability and preparing them to cope with such biases? Are curricula designed to respond fluidly to job-market demands? Are they based upon careful evaluation and analysis of employers' short- and long-term human-resource need projections and technology trends? Are students taught, as an integral part of their curriculum, the necessary skills for job application and interview processes?

If we can design an education system which answers "yes" to these questions, we will truly be addressing the needs of citizens with disabilities. As I noted initially, the primary need of every person with a disability is to have a skill which



is sought in the current job market. Indeed, if our educational system functions as it should, we will produce individuals with such desirable skills that employers will see the economic necessity of making whatever reasonable accommodations are necessary to attract and employ skilled individuals. When this occurs, we will begin at last to achieve the full integration of persons with disabilities.

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\*\*\*Speech made to Long Island Association of Special Education Administrators, February 22, 1983, Huntington Station, New York

Thirty-two years ago yesterday, I was married. One month later, my boss called me in and said, "Frances, I'm re-assigning you to special education. Your eventual goal is to apply the clinical techniques for speech pathology and vocational rehabilitation to curriculum development in special education." Of the two events -- my wedding and my re-assignment -- the latter was far more traumatic, both personally and professionally, mainly because the goal set forth 32 years ago has never been achieved.

Much has happened in special education over the past three decades. The severity and multiplicity of handicapping conditions entering the public education system has completely changed. The growth of segregated special education classrooms, both in the public- and private-school sectors has been phenomenal. In order to understand why I have such a strong sense of failure in my participation in this growth process, perhaps you should know a little about my own education.

Obviously, I have cerebral palsy, a multiple disability. I could not walk more than three or four steps without falling until I was eight or nine years old. Although I always had a verbal personality, my speech intelligibility was still highly problematic on my 30th birthday. Yet, I never attended a special school or a special class. Until my junior year in high school, I attended private schools in New York City. So did

my nondisabled cousins of the same age group. However, to me, such attendance was a symbol of my difference. In my junior year, I transferred to Seward Park High School. Those were the days when regents were required. Since I could neither write nor type, I dictated these three hour examinations and the course work for the five years of foreign languages and three years of mathematics required for college attendance, to an amanuensis provided by the school. I went to Hunter College, Fordham Law School and New York University for my first masters. In the last 20 years, I have often said that, if I entered school today, I would never graduate high school. Rather, I would have been labeled multiply handicapped, placed in a special class where there was no one to model normalcy and permitted to go at my own rate of growth without challenge, motivation or even learning to survive in the real world. This is a strong condemnation, historically rooted in valid theoretical concepts gone astray.

During the formulation of P.L. 94-142, the possible proliferation of segregated special classrooms was discussed -- and rejected. The initial concept was that those disabled students who were then in special education would be mainstreamed into general education and their places would have to be taken by those who were receiving no education. Thus, a continuum of public education services for students with disabilities would be established, with some accountability to ensure that the support services needed to attain the goal of full integration as working, contributing members of their chosen community were identified, so that strategies could be sought to meet needs on a community-wide basis. Issues ranging from parental responsibility to accessing local education administration (LEA's) to funding mechanisms available through other governmental sources prevented real consideration of support services being rendered free-of-charge by the LEA. The concept of such a continuum has never been realized. We must now re-examine where the distortions occurred in order to understand what must be done in the future.

The individualized educational plan is essential if the child is to realize his potential as a contributing adult. However, the structure of the individualized educational program (IEP), as it exists today, may be one of the roots of a self-fulfilling prophecy for failure.

As a special educator, I know that assessment is not a single event at a fixed point in time, but rather it is an ongoing daily tool that cannot be differentiated from other aspects of the educational process. It now seems appropriate to evaluate present procedures used in mandatory assessments -- what are their advantages and disadvantages? Do the instruments used measure what we think they should measure? Are there alternative or more adequate strategies which are not as time-consuming and may relate more the student's educational and academic progress?

As an administrator, as a participant in an interdisciplinary team and as a member of a committee on the handicapped (COH), I know that the IEP consumes too much time. The monitoring roles of program administrators and committees on the handicapped may need redefinition. What an interdisciplinary team is is a different issue, especially in the context of educational progress.

Section P.L. 94-142 very carefully provides that the right to an education begins at age zero for the child with handicapping conditions. Early intervention programs maximize the child's potential and alleviate the need for more costly programs later in life. It is hoped that this year will initiate statewide preschool education for children with handicapping conditions, together with appropriate standards for such programs.

New York has been the national pioneer in special education throughout the century. In the 1960's the school districts could no longer afford to meet the increasing need to educate children with handicapping conditions and so Boards of Cooperative Educational Services (BOCES) were formed to cost-effectively meet increased demands. Ten years later, this trend is being reversed. Perhaps now is the time to re-evaluate and redefine the role of BOCES in special education. In so doing, there are some issues which should be considered.

Over the past decade the vested role of the voluntary community agency in special education has increased markedly. As the public sector began assuming its rightful role in the education of children with handicapping conditions, a tremendous threat was placed upon the established community agency. From the viewpoint of educating the disabled student for community living, the educational programs of the community voluntary agency are even more segregated than the BOCES special classroom. True, the individual child may perform at a higher level in a more segregated environment, but it is not known whether the level of performance achieved in a segregative, supportive environment can ever be transferred to a less restrictive environment. Without such transferability, the value of that performance level to the student's growth and development is questionable.

Networking has been defined as the process of establishing relationships between persons who can commit the resources of the programs they represent in order to achieve objectives commonly held among the programs. This process results in structures, formal or informal, which are mutually supportive. The basic principle behind networking is the exchange of resources. I know of no structure within the school district or within BOCES whereby the expertise of voluntary community agencies is systematically utilized.

Underlying all the issues I have raised this afternoon is the fundamental question of attitudes toward the person with a disability. Recently, I told a group of adolescents that frequently throughout my life I felt like E.T. People too often approach disabled people as if they are members of an outer space species. Repeatedly, I have said that each of us have biases toward the disabled and towards anyone else who is different from us. In education, such biases too frequently lower expectations from the student, as if the teacher and curriculum administrators and planners develop the program plan for the disability and not for the individual. The work of the late Dr. Mark Gold indicates that even the profoundly retarded individual has some cognitive and abstracting abilities. We, in education, probably eradicate these abilities before the child is seven or eight. Are we so



time-bound by the ancient conception of disability that we fail to recognize what more recent research has demonstrated?

This afternoon I have tried to stimulate your thinking in the hope that you will review the purposes and goals of special education and the BOCES role in educating children with handicapping conditions. Highlighted among the issues to be considered are:

...Preschool education: What are the attitudes of BOCES, particularly in assuming the primary responsibility for educating children with handicapping conditions in the three- to five-year age range?

...Mainstreaming: Mainstreaming cannot occur without support services from specialists. The regular classroom and the regular teacher need a resource to assist in assimilating the child who is different into the classroom structure. Should BOCES afford the support services to a number of school districts, rather than render the educational services directly?

...The concept of the money following the child: In New York State this is done with a two-year lag. Neither BOCES nor local school districts perceive this as occurring. Why?

...The Individual Educational Plan (IEP): There must be a re-evaluation of the IEP process and its contents. Is it providing a continuum of education which will produce a self-reliant individual, or is it segmenting the child into a series of years which virtually result in glorified babysitting?

...The roles and responsibilities of individual therapy in the educational continuum: We must ask, "Do all children with speech and language deficits really need the individualized services of speech pathologists, or can the needed language/learning be better accomplished in a group educational setting, perhaps with consultation of a speech pathologist?" The same questions may be asked about physical and occupational therapy.

Over and above these questions are the issues related to what is education and what is parental responsibility. However, I should point out that, if we ask these questions concerning services to the disabled child that are so basic to

the realization of adult potential, we must ask the same questions concerning financial support for intramural sports and other activities which have in no way proven to be essential to the individual growth of the nondisabled student.

All projections demonstrate that, by the late 1990's, traditional sources to meet labor-market needs will be inadequate to maintain the economies of this state and this nation. Sources like the disabled and the elderly must be trained to fill these needs.

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\*\*\*Speech made to College Coordinators of Disabled Student Service Programs, March 14, 1983, Albany

Tommy was born deaf. From the earliest diagnosis, his parents were advised to train him in oral language and not to put him in a special school for the deaf. At the age of 18, Tommy entered one of the SUNY colleges. He was a gifted artist; however, his communication skills -- his ability to understand language -- were barely on a primary level. Tommy was a full-time student at the SUNY college where his coordinator of disabled students knew him well. Upon completion of his fourth year he had barely achieved the junior year level. His parents began to wonder if he was a perennial student. They worried about his future. Would he ever be equipped for self-support and independence?

Like Tommy, I too was born with a severe disability. I have often said that I am grateful that I do not have to go through school today. Since I grew up in the days before the plethora of special education and other special services for the disabled, I was mainstreamed. Traditionally, we are taught that the severely disabled can make it academically if they are allowed a slower than normal pace. I was 15½ years old when I entered Hunter College. I never carried less than 16 credits a semester. Yet, in my freshman year, I went out and got a part-time job, not that I needed the money but because all my friends had to have part-time jobs to go to

college and I couldn't be any different than they were. I was able to do this because I grew up in another educational era when such achievements were not unusual among students who were not disabled. The difference lies in the fact that I, with a severe multiple disability, was permitted to achieve this normal pace. No one said to me, "You can't do it because you are disabled." Or, if such statements were made, there were others who helped me find ways to succeed. I wonder if students with disabilities today perceive that they have the same latitude and the same types of support.

Many years have passed since those days. I have done many things in my life, most of them, I hope, good. I have worked among persons with mental retardation, cerebral palsy and developmental disabilities for over 40 years. I have earned several graduate degrees. Yet, my most valuable learning experiences for living stem from the part-time job which I held as an undergraduate -- for it was there that I began to learn:

1. Time management so that I could achieve a balance between maintaining my grade average, working, continuing my clinical therapies and participating in extra-curricular activities so essential to a well-rounded adolescent.
2. Roles and role-playing in the world of work: Before college, like most people with a severe disability, my world centered about me and my needs. I was first hired as a file clerk -- I, who couldn't tie her shoes, button and zip, now had to handle papers without mangling them and get manilla folders into overcrowded file drawers. Low man on the totem pole in the main office of a large agency, I also served as receptionist and telephone message taker. The job requirements and the needs of those with and for whom I worked had to be met regardless of how I felt or what I preferred doing.
3. At the same time I learned to develop adaptations and systems to meet the job's demands -- tasks which to this day I cannot do the same way that most people do them.
4. At a recent meeting on job development and employment, citizens with disabilities seemed affronted by the

concept that they had to take initiatives in seeking employment. While their reaction was partially due to their obvious lack of skills in interviewing, job applications and similar activities, these deficiencies do not account for the depth of their reactions. They honestly believed that jobs should be handed to them without effort on their part. Knowing how and when to take the initiative -- something most people learn from childhood as a dividend of life experiences -- is overlooked in those who are so disabled that they do not have usual social learning experiences in their formative years.

These and many more skills of living are so essential that one wonders when those with severe disabilities will be given these learning opportunities.

It seems to me that colleges have the greatest potential for preparing persons with disabilities for their rightful roles as productive contributors to their communities. Yet, I wonder how well they are developing this potential, how well they are seeing the student first and the disability only incidentally?

In the late 1960's and throughout the decade of the 70's, the human services field promised great potential for employment. Many colleges and universities developed degrees in human service as if the generalists -- the jack-of-all-trades and master-of-none -- would have a skill that would be marketable in the job market. Reaganomics has put an end to such conceptualizations.

However, this was never a viable idea for students with disabilities. The first need of such an individual is to have a skill which is desired in the current job market -- so highly desired that the employer is going to make whatever reasonable accommodation is necessary to acquire this skill. In addition, the individual must be able to use the skill productively. I think of a friend of years-gone-by who earned his Ph.D in psychology, cum laude, from Columbia University, but never found a job. Because of his inability to speak intelligibly or to write or type, there was no way that his skill was marketable.



There are those today, as there have been for all the years I can remember, who resent equating higher education to job market skills. They claim that "education for education's sake" is sufficiently self-fulfilling. Throughout my lifetime I have noticed that people who have this viewpoint do not have a disability. In addition, they are self-supporting. The goal of the person with a severe disability is to be like most other people: to earn a living, to be accepted and to have the same quality of life as people around them. To give them an education which is not geared to this goal has always seemed a great disservice -- because you are raising levels of aspiration without supplying the individual with the tools for realizing these aspirations.

As I have said before, colleges have a unique potential in the education of individuals with disabilities. I have already mentioned the importance of acquiring marketable employment skills. In this age of computer technology that is only one element.

All my life I have known that I was different -- my greatest difference lay in the way other people treated me. No matter what I did, what I achieved -- there were those who would never treat me as a co-equal or even as a person with sensitivities. If this is true of me, who has achieved -- or surpassed -- all goals in life, how greatly these biases must impact on those who are different and, by reasons of age, personal experiences or choice, have yet realized their goals.

As you examine what you are doing with and for students with disabilities, many of whom may be mainstreamed for the first time in their lives, ask yourself a few questions.

How are you, as educators, preparing students with disabilities for life, despite existing biases?

What have you included in the standard curriculum to teach them to cope with these biases?

Are they learning job-seeking and employment maintenance skills?

What are you doing to help their fellow students and your fellow faculty members to overcome their biases?

Are you teaching students to assume responsibility for their actions?

Are you extending so many privileges in the name of reasonable accommodation until you create a backlash which reinforces biases?

Are you preparing students with disabilities to give to others as well as to take?

Are you educating them to appreciate that others have needs that are just as important as theirs?

Are you challenging them, making them stretch a little beyond their present limits, to acquire what they need or desire?

Are you, as educators, being too over-protective?

Positive answers to these questions divulge the basic responsibility of coordinators of disabled student services. Assuming that coordinators are an integral part of the university team, it is their responsibility to see that the university or college, in educating the student with a disability, provides the fundamental criteria for education inherent in these questions.

The coordinator should serve as a mediator between established curricula, rigid, perhaps biased faculty who have their own preconceived notions of what they demand from the college student, and the student with a disability who comes to you somewhat unprepared for living an integrated life on campus. Coordinators are the negotiators who also provide a support system which encourages the development of an alumnus who is of value to him/herself, the community and who is a credit to the college. This responsibility, as critical as it is to the well-being of both the student with a disability and the college attended, is not really one of advocacy in the technical sense.

A concept seems to have arisen that anyone employed in the helping professions is an advocate. This is not true. Advocacy is a specifically assigned role, autonomous or semi-autonomous of the system upon which it impinges. Thus, not only must you be specifically assigned to the role of advocate, but it is doubtful whether a true advocate can be paid by the system in which that advocacy functions.

Another myth is that an advocate should attempt to fulfill whatever needs that individual verbalizes, regardless of the

reality of the particular situation. And so, Tom was allowed to continue in college for four years when his greatest deficit was in language comprehension, a critically important area of expertise at the baccalaureate level. His advocate never chose to say to him and his parents, "You can't make it unless you first develop realistic, adequate communication systems."

Client or citizen advocacy is designed to assist the individual, making the system more responsive to his or her needs. The purest form of client advocacy is self-advocacy, i.e., teaching the individual techniques to successfully make systems more responsive to his or her needs. It is this training for self-advocacy which is most essential for individual survival in today's world.

The assigned topic for this address was "The Art of Advocacy." That art is a combination of realism, flexibility and knowledge. Its pinnacle is achieved when there is recognition that advocacy may not be the desired role in a given situation. The role of college coordinators for disabled student services may not be that of an advocate in the technical sense. It may be a role of a support system, enabling each student to develop maximum potential, including teaching the student how to constructively advocate for whatever is needed. Such a support system role definition will enable the coordinators to fulfill their assigned role as an integral part of the university team, thus surpassing any accomplishment which an advocate can hope to achieve.

This is truly an art.

*(Similar remarks made to Association of Two-Year Colleges, April 23, 1982, Rochester)*

# Employment

\*\*\*Opening remarks made to meeting of Region I President's Committee on Employment of the Handicapped, March 24, 1982, Saratoga Springs

Things have been happening in New York State for the last nine months or so. To be quite frank, we have been stirring up a lot of dust. What we will have when it all settles down is still anybody's guess, but I think that we have managed to raise a level of consciousness at a time when the national administration is trying to lull us into a semi-comatose state with a bunch of platitudes with which we all agree. I have no quarrel with the intent of reviewing what is being done and coming up with better systems of services in order to better integrate citizens with disabilities into society.

However, I do not believe in "throwing the baby out with the bath water." I do not believe in creating a situation in which increasing numbers of disabled people are doomed to unproductive lives because we couldn't afford proven services while we were waiting to create new models. If such an approach is going to help this nation's economy in the next decade, then I better go back to first grade.

I hope that, as a result of the next day and one-half, we of this region can develop new strategies, make new alliances, network with other established groups such as the Governor's Conference, the Association of Directors of Mental Retardation and the countless other regional and national groups who are as upset as I at what is being done to human beings -- some yet to be born -- in the name of national economy. It is my dream that we will emerge with an action plan. This



nation cannot afford to sink the Northeast. Nor can it ignore what needs to be done for -- and with -- a minimum of 15 percent of its population to create a more sound national economy.

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\*\*\*Remarks made to the Client Employment Program, Office of Mental Retardation/Developmental Disabilities, March 24, 1982, Albany

The special project in which you are working is one of many ways that can train people like you and me to work -- and to work just like other people -- in places where all kinds of people like to work. Therefore, this project is good. You have shown that you can be mail clerks, or maintenance men and women, or grounds people, or teachers' aides, or living-area assistants. You can be trained to work in any of these and many more jobs, depending on what you like and want to learn to do.

You are receiving recognition today for being a part of one of the best job-training programs. The reason that this is one of the best is because of the work you have shown. Because you do a good job and because you behave like every other worker, many more people know that people like you and me can be good workers.

Why is work so important? To earn money. To be able to buy things. To be somebody. Work is like the key to a locked door. It opens the world. It begins to make us like everybody else. It makes us want to be responsible -- not only for our own selves, but for other people too. It shows the world that you and I are people too.

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\*\*\*Remarks made to AFL-CIO District Council 37, May 8, 1982, New York City

As I thought about my presentation to you today, I found that I was more "freaked out" about what I could say

to you than I have ever been in over 200 presentations that I have made around the state in the past year and a half. In fact, I was so concerned about this speech that I began to wonder why and I found there were several reasons.

To me any presentation before a major union in this state is of paramount importance. I believe that no real integration into the quality of job and life security can occur for citizens with disabilities without the full participation of major unions in the policy and decision-making processes. I have often been misinterpreted because of my differing speech patterns -- I am anxious that such misinterpretations be minimized today.

I have been a distant admirer of Victor Gotbaum for years. Mr. Gotbaum, you don't know me. I have avidly watched you on television and often dreamed of an opportunity to personally meet you. The idea of speaking in your presence frankly frightens me.

Perhaps I am a little behind the times, but, when Geri Ruth informed me that one-quarter of the membership at this meeting would be persons who are disabled, I wondered if I was not in much the same position as the preacher who gives his congregation a sermon on not coming to church. This is obviously a union that knows the value of the disabled worker and has provided equity in employment to such persons. What can I tell such a union that would be of value to the membership?

The New York State Office of Advocate for the Disabled is mandated to work with the State Legislature, state agencies, statewide service providers, citizens with disabilities and families of children with disabilities. We also provide technical assistance to localities in establishing workable local councils on the disabled which could have similar impact on issues related to the county or municipality. Here in New York City, many years ago, a mayor's office on the handicapped was established. I have heard today its staff is at least twice as large as our office. We are available to any locality for technical assistance, but when there is an established local office, we cannot give that assistance unless requested. And so, when Geri asked me to tell you how we

are working with the various city departments -- since they are your areas of prime concern -- my feelings of frustration and failure multiplied.

My office, as it has been reorganized within the past year, defined its function as that of systems advocacy. This means that we work within the established system for change which is needed to create an environment in which persons with disabilities are better integrated into employment and community life. Throughout history, meeting the needs of people with disabilities has always been an add-on, something extra, rather than something thought through within the mainstream of policy and decision-making. And so, in times of economic stress, these initiatives, the programs and services, are among the first to go.

When President Reagan was elected, I mourned for the country in general, but I had no real fear for what had already been established through over forty years of concerted effort in federal legislation for persons with disabilities. His record as Governor of California was extremely good on these issues. In addition, it was the International Year of Disabled Persons. As I often have said since, may the disabled never have another year like 1981! However, this being the National Year of Disabled Persons, I fear that 1982 will be even worse.

After I recovered from hysteria over Reaganomics, I began to question the reasons for this rush to regression. Thoughts arose about a group of extremely wealthy men using the poor and disadvantaged to destroy the middle class so that they could rule the country. One night as we were driving back from a public appearance, my driver said to me "You know, until I got this job, I never thought of people with disabilities as working or living like anybody else. I always thought that, if you were disabled, you just got Social Security and that was the end of it."

Suddenly, this remark brought reality into focus. How many people have this concept? Who are the people who are the real enemies of the disabled and otherwise disadvantaged? Are they the special education teachers and the school administrators who are informing Washington that P.L. 94-142

is too expensive and too debilitating on the tax dollar? Are they the governors of the states who are pressuring Washington to change the 504 regulations -- not only because of cost in local tax dollars, but also because of the tremendous expenditures when the accommodations are not workable and are not in use?

Who is the enemy? Is it you and I? Each of us, from our first social interaction, is brainwashed against the disabled or anybody who is different. Judeo-Christian tradition itself implies that the disabled or the deformed cannot achieve the same status as everyone else. And while this concept has changed within the past two or three decades, there are elements and fragments which remain within the unconscious of all of us. It is good to give to charity. We give to the disabled as charity. But when it comes to a choice between me and thee, who's going to win out?

I was startled a couple of weeks ago, for example, when I learned that the transfer of 504 responsibility to the Justice Department and the mandate for revisions was an initiative of President Carter and not President Reagan. To me, this indicates that, regardless of what administration is in Washington, Albany or even New York City, the present backlash against the concepts of the "great society" will not diminish, unless we understand what is happening and develop new strategies so that the needs and the issues we are concerned about will become the issues and the needs of everyone.

This can only be done if we begin to network, to talk together, to exchange viewpoints so that we understand one another.

The key to integration for most people with disabilities is employment. Over forty years of documentation repeatedly shows that the qualified worker with a disability makes an excellent employee, an outstanding union member and a responsible citizen. But the facts don't count anymore. What does count is what people perceive, or think, the facts to be. You know this. For example, nationwide there is a public perception among the middle class (those people whose incomes are between \$15 and \$60 thousand a year) that unions are the cause of this economic mess we are now in. I have



heard this straight across the country from people who were enthusiastic union supporters or members 10 to 15 years ago. Today, listing all the facts in the world to the contrary does not change their minds. Once we understand who the enemy is and what the hangups are, then we can develop strategies, not only to keep what we have gained in the past, but also to develop new initiatives.

Let us go back to the casual remark of my driver. If the image is that people with disabilities are but a drain on the Social Security fund and not productive, responsible taxpayers, as the majority are, then how can we change that image? Or do we share the feelings that my driver expressed?

For example, in that wonderful New York State version of the AFSCME public service announcement in which this union plays an outstanding role, you are pictured as able-bodied persons giving to the disabled. Yet, one-fourth of your membership is disabled. Wouldn't it carry a weightier message if you could also convey the idea that people with disabilities can be givers as well as takers?

Another example may be found among workers who are disabled during their work life. I am confused by the absence of established programs to rehabilitate workers and return them to the work force. My confusion abounds because I realize that my perception of the problem has developed through tunnel vision. I don't know all the facts involved. I don't know the reasons why unions, for example, have not seen the need for this type of work security. When I have asked, I have been told that employers are reluctant to retain the worker who has become disabled on the job. When I have confronted some of the major employers in this state about these problems, they tell me that the unions would prefer to keep their members who become disabled on compensation. I am highly confused. I do not know what the facts are. I feel that I should be coping with this area of concern; yet, I can't as long as I am so uninformed -- for fear of being a bull in a china shop.

Therefore, today, I come to you with a plea for help. There are four decades of proof that the worker with a disability makes a good worker, a highly desired union member,

an active citizen of the community and an "overburdened" taxpayer. Management says it wants workers with disabilities, provided they are qualified to do the job. Some also say that the skilled worker is so badly needed that they are willing to make reasonable accommodation to obtain such a worker. I have always believed, as I was taught at Hunter College in the days when the AFL-CIO was first being formed, that unions exist to protect their membership. Obviously, there is a missing piece between these two facts of which I have no knowledge. All I can do today is plead with you to help find this missing piece. The Office of Advocate for the Disabled can be used as a strategy to seek mutually beneficial resolutions, whether they be in the area of legislation, regulation or just mutual agreement. For as long as there is an Advocate's Office, this office will serve as a neutral ground upon which all sorts of people can be brought together to discuss any issue without prejudice.

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\*\*\*Speech made to New York State Association of Rehabilitation Facilities, September 10, 1982, Albany

A recent advertisement reads: "IBM believes the handicapped are an untapped resource." While there are those who would argue for the use of the word "disabled" in lieu of "handicapped," IBM's position is shared by most Fortune 500 companies, especially in view of recent predictions that traditional sources of labor are on the decrease because of declining birth rates in the past two decades. Additionally, recent statistics show an increase in number of persons with disabilities: some claim an expectancy that one person out of 10 will sustain a disability during his/her lifetime. While the incidence of mental retardation and developmental disabilities has markedly declined in recent years, the anticipation is that it will now increase due to recent curtailments in prevention programs.

The downside of these statements is that industry claims that the majority of persons with disabilities are not trained

as workers qualified to meet the labor market needs of the eighties. Both industry and organized labor verbalize dissatisfactions with current practices in vocational training and sheltered workshops, as well as in higher education in general. Since there is evidence that these perceptions have some justification, I would like to take this opportunity to explore with you a few of the issues which deserve immediate attention. As I do this, I ask that you momentarily try to forget your immediate problems in the current fiscal crunch. Developing the strategies which will determine how we get from where we are to where we want to be is contingent upon understanding how we, as service providers, must re-evaluate the way in which we operate.

The Willowbrook Consent Decree hallmarked a revolution for most services and programs throughout the state. Community residences came into being by the scores. Day treatment/day training and new workshop programs grew, not only in size and number of personnel, but also in the variety of programs offered. The nature of the clients served radically changed. Most importantly, our perspectives and our levels of aspirations were drastically altered. Now we are faced with an economic crunch.

Currently, the continuum of what is done for persons with disabilities is most costly. However, if we continue to plead for keeping what we have -- unaltered except for expansions -- and justify continuation on humanistic grounds, these programs will become increasingly expendable in times of economic crisis. No one is going to worry about the "poor little handicapped person down the street" as long as they are having difficulty in purchasing what they believe they need for a good life. It, therefore, behooves us to develop strategies and programs whereby the "good life" for the average citizen is dependent upon the independence and self-support of every person with a disability.

We cannot do this unless we ourselves believe it possible. What are our attitudinal biases toward the disabled? What are the attitudinal biases of our staffs? Our co-workers? The members of our boards of directors? Are we, as individuals, still in the mind-set of the era in which we started this field

-- the forties, the fifties, the sixties? Programmatically, what are we doing to reinforce the imagery of everlasting dependency of the severely and profoundly disabled? How do we change our methodology, our approaches to the client? How do we restructure our programs? I know that many of you have begun to do this. Share this information. I know that there are legal and regulatory restrictions preventing you from doing more of this. Identify them. Help work out reasonable modifications which do not impinge upon documented monitoring requirements. Are the standards appropriate for what now must be achieved? If not, why not?

As professionals, we have been trained to be myopic -- to advocate for our own programs and services and avoid getting too involved in areas beyond our domains. Now is the time for re-education. If the educational continuum is not providing the basic skills to train qualified workers to meet current labor market needs, get involved in the educational process through memberships on the committees on the handicapped (COH) and on the school boards so that the quality of education will meet these needs. Develop and provide continuing education for the Board of Regents' member from your region.

By the same token, perhaps we have to revise our own methods of service delivery. Unquestionably, we have to increase our communication and involvement with corporations, labor unions and the retail mercantile community. Too long have our programs and our decision-making been isolated from the mainstream of these groups -- resulting in mutual dissatisfaction and misinformation which we can no longer afford. Most importantly, learn to share full partnership at all levels of decision-making with disabled persons and develop strategies for training such persons in exercising these responsibilities judiciously and independent of your own pre-conceived concepts.

In the last decade, due to the dependency on governmental funding, the natures of our boards of directors have changed radically. When I was a young professional, members of the board of directors were responsible for raising the major portion of the agency's budget as well as overseeing its



disbursement. I have a distinct feeling that this is no longer true. Although no one wants to go back to those "lady bountiful" days when the members of the boards of directors thought that they were executive staff, I urge each of you to review carefully the structure of your bylaws and the composition of your boards of directors. Are they appropriate to the new era upon us? Will they be responsive to the changes that must occur within the next decade?

As a not-for-profit voluntary agency, you are legally limited in the amount of political action in which you engage. However, you have a natural constituency which can independently do this job for you -- provided you recognize their existence and network with them as co-equals. Citizens who have disabilities can help you, but first you must change your attitudes toward them. It is of direct concern to you that they are registered and that they vote. Are polling places in your community accessible? If not, what have you done about it? Are the restaurants and retail stores accessible? If not, what have you done about it? What have you done, both as an individual and as an agency executive, to ensure that persons with disabilities are integrated into the community?

As you examine these questions, I submit to you that group trips to local malls and similar agencies reinforce negative biases towards persons with disabilities. Greater numbers make differences more obvious -- like freaks in a side show. What may be needed at this juncture is increased communications -- at the topmost levels of management -- between providers of vocational and residential services to set realistic, socially acceptable guidelines for currently reported practices in enabling persons with disabilities to exercise personal freedoms and choices.

My allotted time does not permit me to go on and to point out that the need for integrating modern technology into vocational programs is critical, and that such integration can be attained only by coordination and cooperation with industry and with the development of new enterprises within New York State. Hopefully, NYSARF's current undertaking with Projects with Industry (PWI) will lead toward the development of partnerships with corporations, encompassing

such areas as equipment loans, vocational training at industrial work sites and contracts to supply qualified workers rather than to manufacture or package products.

A new job-training bill is presently pending in Congress. All predictions are that it will pass in some version. This new law can provide our single most important legislative base for the next decade, provided that we develop the wisdom and the flexibility to use it properly.

The choice of alternatives for future development are limited only by one's creativity. It is well to remember that most corporations have provided far more in their budgets for advertising and staff development than they ever will set aside for charitable contributions. The development of relationships with the state departments of Commerce, Taxation, Labor and Environmental Conservation may hold greater future promise than increasing demands on our traditional service agencies.

The recommendations of the New York State Commission on International Year of Disabled Persons provides a framework, a plan for the next decade, as to what needs to be done in the face of increasingly limited resources. These are incorporated in the forthcoming report of the Council on State Priorities. The goal has been set: By the year 2000 every person with disabilities will be integrated into the daily life of the community. This is achievable, provided we begin now to develop the needed strategies.

Finally, I cannot close without a personal word. No one knows what the future holds. Twenty months ago, few of you ever heard of Fran Berko. The cooperation and respect so generously given me by the NYSARF members, board and staff helped create lasting progress on issues related to persons with disabilities. I hope that I have earned your confidence -- just as you have earned my gratitude.

## Councils on the Disabled

\*\*\*Speech made to Fairport-Perinton Council on the Disabled, April 22, 1982, Fairport

In 1979, Governor Carey published the Children's Budget. It stated that there are 2.5 million people with disabilities in New York State. This estimate is probably extremely low, but, in view of the present state of the art, an accurate count of persons with disabilities in New York may presently be unattainable at any price, and perhaps irrelevant to present needs.

It is far more relevant that this state adopt a single definition of "citizens with disabilities." As most of you know, Title V of the Rehabilitation Acts of 1973 and 1978 defines persons with disabilities. New York State has never adopted a parallel law.

Today this need is more critical than ever -- not only because of the threat currently posed by the federal administration to all entitlement programs of which the Rehabilitation Act and Public Law 94-142 are a part, but also because many needed initiatives in New York State are not taken because legislators do not understand the nature of the Pandora's box they are opening in passing pieces of legislation to address the needs of citizens with disabilities. The critical issue concerns defining the type of person for whom assistance is sought. As a matter of fact, we know from over three

decades of research that 15 percent of any population in this country has a disability of sufficient severity to require some supportive or rehabilitative services to realize their rightful role as contributors to the community.

When Governor Carey appointed me state advocate a little more than a year ago, there seemed to be considerable confusion about what advocacy is, who are the advocates, and what was the role and function of a State Advocate for the Disabled. As the work of the International Year of Disabled Persons Commission progressed, and as I traveled around this state learning both what the needs were and why this office was originally created, it became apparent to me that a new mode -- systems advocacy -- had been born in my office. As systems advocates, we are sort of brokers between state agencies, the service providers, citizens with disabilities, the State Legislature and the general public -- raising issues in a manner that would lead to affordable resolution for the maximum benefit of this state's citizens. In seeking resolutions, preferably within the mainstream of this state's decision-making, we can enable a maximum number of persons to contribute, not only to their own welfare, but to the welfare of those around them. As Reaganomics began to unfold, this goal seemed even more imperative. One of the most positive bases I found upon which to build a new systems advocacy model was Chapter 638 of the Laws of 1980. It is no secret to those who have heard me speak on various occasions that the establishment of viable, local councils on the disabled by the county or municipal legislature is the highest priority facing those concerned with disability issues.

Historically, at every level of government, those concerned with disability issues have been pitted against each other. Citizens with disabilities are either perceived as displaying no interest or antagonism towards the needs of service providers. Those individuals with disabilities who do support service providers are perceived as "Uncle Toms" or puppets of the service providers. One disability group makes its demands without regard or consideration of the needs of the other. This is equally true of service providers and consumers. Each



perceives the other as a threat to their needs. Those with ambulatory difficulties often show no real concern for their peers who may have communication difficulties, or sensory losses, or who are retarded or have some other mental disability; nor do their respective service providers. This lack of concern for one another has bothered me since my first contact with other citizens with disabilities many years ago. If we don't care about one another's needs, how can we expect others to be concerned about ours?

This philosophical approach is, however, a personal one, and, as such, is no basis for action. What is important today is that we are living in an era in which human services are looked upon in a manner different from what we have known before. Let us examine some of these differences.

Our nation is in the midst of an economic recession, which, from all indications, will get worse before it gets better. Unemployment is mounting daily; small businesses are in jeopardy; costs of life-safety necessities -- housing, food, telephone, heat and transportation -- have had all controls lifted. Having lived through the great depression, I find the situation today of even greater peril. History shows that whenever this country, or any state, is in economic stress, the level and scope of services to disabled people are among the first to deteriorate. Careful examination of these incidences over this century show several contributing factors, the most important of which is of concern today. Issues related to citizens with disabilities have never been a formal part of the decision-making process.

In the current fiscal year, this state may lose as much as \$2.2 billion in federal income and the president's budget proposal for next year seem to project an additional loss of \$2.3 billion. Two and one-half billion dollars of this \$4.5 billion loss is in human-services programs. Because present negotiations on the proposed fiscal year 1983 budget are defined in terms of the size of national deficit, there seems little hope that the proposed cuts in human-service funding will be restored in any meaningful way. To me this means that the programs and services that we have come to rely on perhaps should now be viewed as past history.

This loss will be felt in every community in the state, and no one -- including state or local government -- can compensate for this loss. Aside from mandated expenditures, many decisions on how to spend what remains will be left to the localities. County and municipal legislators will be under greater pressures than ever before in history. Unless they recognize and are assisted in their decision-making by some formal body with expertise in issues affecting citizens with disabilities, the priority setting and redistribution of resources now necessary may deal too harshly with restrictions and eliminations of existing services to disabled persons. The "squeaky wheel" syndrome is most real, provided there is a single, loud squeak. Other groups in need are better organized and, therefore, more vociferous. Their unity conveys a political force which we do not have, even though numerically we may outnumber all other minority groups.

This absence of a unified, political presence also affects our ability to impact on a statewide basis, especially now. Up until this year, service providers and some consumers, either individually or by group, could come to Albany, plead their needs, and get some satisfaction from the legislature, or more frequently, from the executive branch when it concerned the expenditure of federal monies. Now that all such monies must be appropriated by the State Legislature, the deathkneel of this process has probably been sounded. While I am not naive enough to think that the former system has disappeared completely, it will become so complex and tenuous that ultimately more effective input on the local level, combined with the necessary communication among local councils on the disabled, will provide greater returns to all than can be realized through periodic pilgrimages to Albany.

Chapter 638 of the Laws of 1980 prescribes that local councils on the disabled should consist of nine members. However, to be effective bodies, these councils must include in their decision-making processes not only all spectrums of the community concerned with issues related to the disabled but also representatives of local industries, media, local governmental departments and the regional offices of state agencies. If one segment of the service provider groups is not

included, the main objective of local councils on the disabled will not be achieved just as it will not be achieved if the council is not established by the legislature.

My office has, therefore, been advising councils to set up committee structures which are formal workgroups. Technical assistance can be obtained from my office on the structure, function and development of work plans.

You of the Fairport-Perinton council have initiated what seems the most viable model for such a council structure, especially in upstate New York. By forming a council on a town level which will hopefully lead to a Monroe County council representative of all such town councils, the base of decision-making can be all inclusive and, at the same time, impact on every level of government.

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\*\*\*Speech made to Councils on the Disabled Regional Meetings, week of December 6, 1982, Albany, Syracuse and Jamestown

To me, viable, functioning councils on the disabled in every community of this state will provide citizens with disabilities, together with their families, their advocates and their service providers, with an appropriate vehicle for participation in local decision-making. At the same time, the development of strong linkages between local councils and the Advocate's Office will assure that my office accurately reflects your interests and concerns on the state level.

I would like to share with you some of the reasons why I so enthusiastically support local councils on the disabled:

It has become apparent that, in the foreseeable future, the focal point of activity in resolving issues, whether they have local, state or national impact, will be on the community level. The needs of any segment of the community's population may not be attended to unless those needs are recognized by other segments of that community's population.

Historically, the Advocate's Office was established to reflect the statewide needs of citizens with disabilities, their families, their advocates and service providers. As we stand here today, there are so many different groups claiming to represent those concerned with disability issues and verbalizing diametrically opposed viewpoints that no one knows who speaks for the disabled.

I spent many years living in upstate New York, where I was a service provider. I know only too well that needs and resolutions vary from region to region and community to community. For too long, such resolutions have seemed to emanate from some decision-maker in Albany or New York City who is unaware of the specific problems and priorities faced by individual communities. What we need is a reversal of this pattern. We need a method of making decisions based on the realities of communities as seen by those who reside within the community, not as seen by some think-tank far removed from that community.

However, a solution found in one community may also work in a sister community and, therefore, there must be a vehicle to exchange information and ideas in order to band together as a cohesive group to address mutual concerns.

The majority of unmet needs of persons with disabilities are not due to the lack of laws. In fact, in New York State there may be too many laws attempting to help persons with disabilities. Some of the existing laws may even appear to contradict one another. Inadequate implementation of existing laws is a far greater hindrance to realizing the goal that individuals with disabilities be fully integrated into their chosen communities by the year 2000. Implementation can best be achieved on a community-by-community basis. Because of the way state and local governments are structured, the implementation of existing state laws may be purely a local problem. Thus, only local initiatives can resolve such problems community-by-community.

The Advocate's Office's role in encouraging the establishment and effective functioning of the local councils is unclear in certain sections of the state. Therefore, I would like to spend a few minutes on how I see it.



For the reasons already given and many others, the need to establish local councils was deemed so important that I placed high priority on giving all the help that we could to local people in establishing such councils. This does not mean that we run the councils, tell the councils what to do or fund the councils. We are available to localities as consultants to help you get organized and exchange information with one another. We suggest, you accept or reject. We are available to answer your questions, to provide advice and accurate information.

For example, we see a local council as an official arm of county government to advise local decision-makers. We see a local council consisting of representatives of citizens with disabilities, parents of children with disabilities, community service providers, including Boards of Cooperative Educational Services (BOCES) or the local school district, as well as business, union and community leaders. Broad representation may require more people than the nine maximum noted in the law. Such representation may, for example, be achieved through a committee structure, or the legal, maximum number of nine members may serve as the steering committee of the larger council.

I am aware that most of the established local councils do not have this broad-based membership. That does not mean they are not effective beginning efforts. The more that various viewpoints are expressed in the councils' processes, rather than having them run to the local decision-makers on their own, the more effective the local councils will be. You should be aware of this fact. Such all-inclusive councils are like long-range goals, an ideal to work for which will not be accomplished overnight.

We are also looking to you to guide us, tell us what needs doing, tell us what's not working and why it isn't working. For example, I had hoped that in October and the early part of November we would be inundated with calls from all parts of the state reporting that polling places were inaccessible. We received very few calls. Unless we have these specifics, it is impossible to achieve statewide accessibility of polling places, regardless of what state law mandates.

# Introduction to the Legislative Process

As New York State's Advocate for the Disabled, much of my energy has been directed toward activities that will motivate persons with disabilities to become more politically active.

Although persons with disabilities are beginning to enjoy more of the rights and benefits routinely enjoyed by the majority of this state's citizens, nothing near equality exists.

Laws cannot change attitudes or enlighten those who persist in clinging to misconception.

Laws do, however, open doors that assist disabled persons in pursuing their rights to education, employment and personal growth opportunities -- opportunities that encourage independence and participation in the activities of community life.

If persons with disabilities are to fully participate in the mainstream of society, it is mandatory for each individual to become politically sophisticated, visible and vocal.

Failure to exercise one's rights will only reinforce the misconception that disabled persons are categorically powerless and dependent.

\*\*\*Speech made to Legislative Committee of Council on the Blind, March 14, 1982, Albany

In my estimation, an office such as ours would not be necessary if issues related to citizens with disabilities were in the mainstream of governmental decision-making. Unfortunately, they are not.

Issues related to citizens with disabilities are infinite, as are issues related to all citizens. In my lifetime every need of every citizen will not be met. Personal philosophy dictates that when needs are identified, you actively pursue those needs for which there is a probability of winning, while at the same time you adequately prepare for successfully meeting other identified needs in the future.

This is the premise on which we presently function. However, since this office was created by executive order, I cannot guarantee that there will be a state advocate's office a year from tonight -- unless such an office is established by legislation in the current session of the State Legislature, as recommended by the governor in his February 9th State of the Health and Human Services Message.

I will be around as long as you need me to answer any questions you may have. We are here to serve you. Please call.

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\*\*\*Speech made to American Federation for the Blind, June 11, 1982, Albany

I was born with cerebral palsy. That does not mean, however, that my needs and your needs are radically different. It is only in the strategies devised to meet these needs that some flexibility may be required to take account of individual differences.

I had initially planned to address three areas this afternoon. First, the need to understand and become involved in the legislative process; second, the ways in which my office

can assist you; and third, the need to coalesce around a limited number of issues. In a sense, your very presence here has mitigated the extent to which I feel it appropriate to address the need for involvement. You are demonstrating, by your participation in this workshop, that you are well-aware of the importance of the legislative process. Rather than emulate the clergyman or woman who preaches the evils of not attending services to the faithful who do attend, let me move on to a description of the activities of my office, and try to give you some sense of how I can assist your efforts.

As most of you may know, the Office of Advocate for the Disabled has been completely reorganized within the past year. After this reorganization was completed, we put out a new brochure describing our present functions. Today I am leaving with Gerry Miller several tapes of the contents of this brochure. We did not prepare a different mission, purpose or function geared to blind citizens. We have put on tape exactly what the brochure says. I am also leaving brailled copies of my business card with my office contact number.

The overall function of the Advocate's Office is that of systems advocacy, especially as it is differentiated from citizen or client advocacy. Client advocacy is a function of many other agencies, both governmental and voluntary. Our function is to try to make the system -- or what exists -- work to achieve current and future needs of citizens with every type of disability. If existing systems no longer seem capable of meeting such current or future needs, we then act as agents for change. Change may require administrative, legislative or judicial action. While sometimes necessary, resorting to judicial action may be the least desirable strategy for change -- especially when the goal is to get the job done in the most efficient, effective and timely fashion.

Personal opinion further dictates that a systems advocacy office can be most effective when it serves as a catalyst for networking diverse groups concerned with the same issues.

To target our efforts, we have identified five major areas of immediate concern: information and referral, community development, legislation, publications and employment development, particularly in the private sector. Added to these is



a category known as special projects. Special projects include housing, transportation, Social Security, the impact of federal budget cuts and the many other temporal issues which seem to arise with increasing frequency. Each of these areas is far more complex than is initially apparent. For example, within six months of going to work in Albany, it became abundantly apparent to me that perhaps the greatest need in legislation concerning issues related to citizens with disabilities was not in the area of more laws. It was in the area of making all citizens interested in these issues more knowledgeable about the legislative processes. I learned with great surprise in the spring and summer of 1981 that the legislative process does not begin with the convening of the legislature in January. For at least six months before that time, new bills are in the process of being drafted, revised, and compromised and legislators and their staff are frequently involved in these preliminary deliberations. When the legislature is in session, a bill has to be nurtured almost daily if it is to have a chance of passage. Most surprising to me was the fact that over 2,000 bills concerned with issues related to citizens with disabilities were introduced in the 1981 session of the State Legislature.

To share this information, the State Office of Advocate for the Disabled held its first legislative workshop in October 1981. It brought together representatives from state agencies, a wide variety of service-provider groups and all types of citizens with disabilities for two days. Printed copies of the proceedings of this workshop are available. Copies on tape will be available upon request. A second legislative workshop is now being planned for September 9 and 10 in Albany. Similarly, we have had and are planning other conferences related to community development, outreach into minority groups, coordinators of student activity on college and university campuses, labor-market initiatives and a variety of other regional and statewide meetings. Every effort is made to publish the details of these informational meetings -- either in pamphlet form or in "The Advocate," our monthly newsletter -- so that these efforts can be duplicated throughout the state.

As a result of the massive reductions of federal financial assistance available to New York and the resultant fiscal pressures on the state and its localities, it is more important than ever that citizens with disabilities work together to achieve common goals.

You have your own agenda which reflects concerns and priorities which are unique to persons who are blind or visually impaired and to their service providers. What I would ask of you is that in pursuing these issues, you also remain open to and supportive of generic issues, like civil rights, non-driver identification cards, housing, transportation and architectural accessibility, which work to the benefit of all persons with disabilities. Many, if not all of these issues are of concern to you; however, the specific needs of persons who have visual impairments may, in each of these areas, differ from those who have some other disability. When you plan and work alone, seeking those strategies which assist one specific disability group, nobody's needs are satisfied.

Civil rights legislation is an excellent example of this point, because it has been pending for so long. Our office coined the phrase "affirmative integration" to denote what disabled people need by way of reasonable accommodation to exercise their civil rights with equity. At the 1981 legislative workshop, some eight different areas of concern were identified by the different disability groups. If we think of affirmative integration as the issue around which we all can coalesce, and if we unite in our dedication to resolve all eight concerns, persons with disabilities may finally achieve civil rights in law (Chapter 720, Laws of 1982).

Transportation issues provide another example. Here, the needs of the mobility impaired seem to be in opposition to those with other disabilities, both programmatically and financially. What is not realized is that the resolutions sought by the mobility impaired are presently technologically and financially impractical. If all of us could plan together, mutually beneficial resolutions and strategies for their achievement could be realized -- of this I am certain.

Perhaps the single most immediate need for all persons with disabilities today, regardless of political affiliations or

belief, is to become visibly active in forthcoming campaigns and elections. Our office has become highly involved with the state Board of Elections in seeking enforcement of the laws providing for accessibility of polling places in these efforts. Since the elderly also need barrier-free places to vote, we have networked with the Office for the Aging. We have also stimulated the awareness of local groups, since the primary responsibility rests with local election districts.

Recently, in a special election for a single local position, brailled ballots were distributed at tremendous effort and expense. The intent with which this was done was magnificent, heartwarming and deserving of all the praise one can give. If, however, proponents had consulted someone who was visually disabled, they may have discovered that large-type ballots, combined with some tapes of the ballots, would have better served a greater number of visually impaired persons at less cost. They also would have permitted each citizen to vote within the legal limitation which allots three minutes per person in the polling booth.

Why do I continue to raise these issues, especially when I know that you may not want to hear them? It would be so much easier for me to give you simplistic solutions with which you all agree. There are many reasons.

First and perhaps foremost, our nation has finally realized the depth of its financial troubles. In the search for scapegoats -- and for the first time in my memory -- programs for persons with disabilities are caught in a backlash. We must now overcome the cause of that backlash.

Even when times were good and monies for programs seemed plentiful, our achievements never seemed to satisfy all of the basic needs. Programs, services and agencies flourished, but did we achieve full employment and full integration into community life? If not, why not? I suspect that discovering the answers to these questions will also reveal the causes of the present backlash.

Recently, I have been raising the question "Who is the enemy?" -- Reaganomics, or each of us and our advocates? I ask you this question. Do you preserve what you have achieved and achieve what you need by continuing to fight

for your needs alone? Or, should you demand an equal voice in a greater federation where such unity can gain recognition as a force within the mainstream?

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\*\*\*Speech to Coalition of Disabled in Action, November 6, 1982, Albany

Professional lobbyists earn their living by doing political action for a variety of interest groups. Last week, I heard that there are 314 thousand political action committees (PAC) attempting to influence the Congress and the federal government. In New York State, well over 40 such groups have full-time offices in Albany. During the legislative session, there are countless additional people who spend as much time in Albany as any state legislator.

The basic power of any political action group stems from two sources: money and the ability to deliver thousands of votes. To borrow from one of our workshop speakers, political action always follows the golden rule: If you have the gold, you rule. Political action groups give substantial amounts of money to campaigns for any elective office. This, plus the perceived ability to deliver to any candidate thousands upon thousands of votes, is what makes a political action committee effective. As far as I know, or I am able to find out, people with disabilities do not usually have thousands of dollars to spend to get their political candidate elected; nor can any one group of disabled people deliver the thousands of votes necessary to be perceived as an effective PAC.

Let's take your group today. There are about 40 people in this meeting. Let's assume that each of the 40 people represent 10,000 votes. Am I being generous? Yes. Do I think that each of you represent and can deliver 100 votes, let alone 100 x 100? No. But let's assume you can. How many people with disabilities live in New York? Frankly, we don't know. The lowest estimate which I have seen comes from the Office of Vocational Rehabilitation which estimates there



are two million persons with disabilities in New York State. I think this is far too low, but let us assume for the moment that there are only two million people with disabilities and that each of you represents 10,000 of the two million.  $40 \times 10,000$  is 400,000; 400,000 is only one person out of every five. If you only represent 1,000 people it would be one person out of every fifty. Remember too that this series of examples is predicated on the lowest estimate of this state's disabled citizens.

It seems to me that in talking about developing successful political action groups in relation to persons with disabilities, we cannot copy what other successful PACs are doing. We have to develop new strategies that would be just as effective and achieve the same goals. May I review a few that I have been suggesting every time you have heard me speak?

Coalesce with other organized groups representing people with disabilities. While I was on the phone yesterday, my secretary was answering an information and referral call from someone trying to find the address for the Alliance of Disabled Persons. None of us, including Roxane Brody who happened to call in, had ever heard of this group, but we learn of new groups here and there many times a week. Why do we need 50 million groups? Because there are so many groups, each claiming to speak for people with disabilities, this multiplicity of sometimes divergent positions provides a perfect cop-out for any decision not to address our needs.

Coalesce with other groups that may have one or two needs which are similar to some of your needs. For example, architectural barriers also represent a significant obstacle for the aged. The coalitions of senior citizens, such as the Grey Panthers, may be one of the most powerful lobbies in this nation, as well as in this state. I have been saying this for years, not to detract from your efforts or to minimize your needs but rather to encourage you to align yourself with others who may already have the clout to help you.

Service providers, by virtue of their boards of directors, represent substantial wealth. That is why they seem to get far more from government than organizations of persons with disabilities. Money begets money. I perceive that the ser-

vice providers are getting to a point where they need you. They have to coalesce because of what has happened within recent months, both in the budgetary process and as a result of the effects of Reaganomics. They can no longer go one-by-one and get what they need from either the legislature or the administration. Because they are quickly reaching the point at which fiscal realities may force them to compete for resources, only those who are offering services which are truly necessary can survive. To assure that they indeed offer such services, service providers need your input. You don't like the service providers? You don't like their manner of delivering services? Yet, when you talk about effective political action, this is irrelevant. Politics make strange bedfellows and hopefully you can change the service providers by working with them. At least in my experience, the most effective way to get change in any group is to become part of that group and work from within for change, rather than to stand apart from the group and complain about it.

Among the most powerful lobbies in this state are the Association of Counties and the Association of School Boards. These effective lobbies emanate from the grass roots. What your local county and local school board decide is represented by their lobbyists in Albany. The effective development of local councils on the disabled, as an arm of the county legislature, is a way to tie in to these established entities. Some of you here today are involved in this process; others of you are not. As the Advocate's Office continues in its endeavors to provide technical assistance to and strengthen these local councils, as well as to coordinate the efforts among the various councils, I can only advise those of you who are not participating to reconsider the efficacy of such participation.

The four strategies that I have just reviewed are but a beginning, but they are essential to any future strategies which may be developed.

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\*\*\*Speech to the Congress of Handicapable Employees in State Service, February 16, 1983, Albany

When I was invited to address you I was given the topic of "Legislation and the Disabled Community." Legislation is just one of the many aspects which will afford persons with disabilities equity in living as citizens of New York State. Departmental regulations, administrative processes, public policy and attitudes toward persons with disabilities impinge upon existing inequities as much as or more than legislative action. Tonight, however, I would like to review some of the major legislation affecting persons with disabilities which was enacted during the 1982 legislative session, discuss a few of the legislative priorities for the 1983 session, and finally, consider strategies which may improve our political clout in the legislative sphere in the future.

In reviewing the annals of the State Legislature, I can find no other single year in which there was a record of accomplishment which paralleled the achievements of the 1982 legislative session. Out of a total of 2,000 bills pertaining to disability issues introduced into the last session of this State Legislature, 57 bills were enacted into law which directly affect persons with disabilities. I would like to briefly review the provisions of some of the major enactments.

Chapter 544 establishes a referral and assessment process for children with handicapping conditions who return to this state for adult services after placement in an out-of-state facility. This comprehensive planning process will facilitate the transition of such persons into New York's adult services programs.

Chapter 718 established a permanent statutory basis for the Office of Advocate for the Disabled. Prior to February 1 of this year, the effective date of Chapter 718, our office had existed pursuant to an executive order issued by Governor Carey in 1977. The enactment of our office's statutory basis manifests a permanent commitment on the part of the legislature to assure that, in an era of increasingly scarce fiscal resources, the needs of persons with disabilities are addressed

in a meaningful and appropriate manner. This statutory commitment will provide our office with a greater capacity to promote the increased coordination among entities providing services to persons with disabilities to realize our goal of achieving full integration of persons with disabilities into community life.

After 17 years of effort, there is now included -- with the signing of Chapter 720 -- in the Civil Rights Law of this state a provision that no person shall, in the exercise of his or her civil rights, be discriminated against because such person is a person with a disability. This law is important to persons with disabilities not only symbolically -- since it is the first time our state has declared discrimination against persons with disabilities to be a violation of one's civil rights -- but also practically, because both civil and criminal penalties are prescribed for violations of the law. Among the many advantages of Chapter 720 is that the Attorney General of New York State can now intervene on behalf of disabled people whose civil rights are abridged.

Chapter 744 established independent living centers at 17 primary locations across the state. The federal government had provided funds for the establishment of nine previously existing centers -- much of that funding, however, expired by the end of the 1982 federal fiscal year. The continuation of the existing centers and the establishment of new centers provides New York State with a network of community-based organizations which will assist in areas such as housing, peer counseling, homemaker services, health care, job training and information and referral services.

The 1982 session of the legislature produced two bills of particular interest to state employees or prospective state employees. Chapter 543 authorized the State Civil Service Commission to permit noncompetitive state employees employed under the 55-b program the opportunity to take promotional examinations. Prior to this enactment, many 55-b employees were, as you know, not eligible to take certain promotional examinations because they lacked state service in competitive positions. In addition, Chapter 196 amends the Civil Service Law to permit hearing-impaired persons to use sick leave to



obtain and train guide dogs. Perhaps in the question and answer period which follows, the issue of the status of 55-b employees, in times of major lay-offs in state government, will be raised as well as some of the present undertakings of the Civil Service Commission in regard to state employees who have disabilities.

What were the reasons for the successes we experienced in 1982? First, I believe that attitudes and concerns about the needs of all persons with disabilities are beginning to change in the minds of decision-makers in state government. Many disability issues have been vaulted into the mainstream of the decision-making process. In the future we must continue to insure that issues relating to persons with disabilities are raised and debated during the early policy-making and planning stages -- and not as an addendum during or after the implementation stage. This does not mean that all our needs have been or will be met. Much needs to be addressed in the 1983 session of the legislature and in the years to come.

Before discussing the 1983 legislative priorities, I would like to say a word about how these priorities are set. The Advocate's Office will support any proposed legislation which it believes is needed on a statewide basis and is potentially achievable. Need is determined from many sources. The inquiries that annually come through our own information and referral system point out areas of statewide need in a most informative fashion, and the feedback we get from groups such as yours and other organizations of disabled persons in this state are carefully remembered.

Experience has shown that too many people in government serve as "yes men" to the so-called consumer groups, knowing that the proposed legislation requested stands no chance of passage in both houses of the legislature. This we refuse to do. We would rather tell it as it is and then figure out a way of resolving the issue successfully. For the 1982 and 1983 legislative sessions, the Advocate's Office has come out with a very small legislative package. However, we actively support those bills of merit which are proposed by other state agencies, state legislators and a variety of consumer groups. Fiscal constraints in the state budget are a

major consideration on a year-round basis. We are seeking ways to modify and improve the state delivery system, including monetary savings which can then be transferred to needed new initiatives.

The legislative priorities for 1983 include a nondriver identification bill. This is a major legislative priority for those who have epilepsy and those who are blind. This measure would permit those who do not possess a driver's license the opportunity to obtain a non-driver ID. Many persons with disabilities and elderly persons constantly face difficulties in making such simple transactions as paying for a purchase by personal check because they do not possess the most universally accepted form of personal identification in the state -- a driver's license (Editor's note: Chapter 295, Laws of 1983).

Another high legislative priority for 1983 is to secure passage of a uniform and consistent prevention program for preschool-aged children who have severe disabilities. I believe that such statewide programming is affordable and within the limitations of current expenditures. The benefits derived from a well-run state prevention program will not only provide an immediate benefit to the recipients of such services, but its effects will exponentially expand as those children grow to become more productive and better integrated members of our society. Let us hope that in the new legislative session an approach can be formulated to accomplish this affordable, needed program.

The statutory establishment of one uniform state definition of disability will be sought, which would be essentially the same definition as utilized in Title V of the federal Rehabilitation Act of 1973. Such a definition of disability would coordinate state and federal efforts to end discrimination on the basis of disability. Under such a proposal, the scope of protections afforded in the State Human and Civil Rights Laws would be more consistent with protections incorporated under the Rehabilitation Act.\*

Another high legislative priority is to promote increased employment opportunities in state service, private industry and in those businesses which contract with the state to provide goods or services. In his State of the State Message,

Governor Cuomo stated that jobs for the disabled are particularly important and will be a matter of special concern in his administration. It is understood that Governor Cuomo is planning some major initiatives in the field of affirmative action which will include persons with disabilities.\*

To effectively pursue these priorities, it is important that we all become involved in the decision-making process. We must understand the process and know when, where and how to get involved. Successful political strategists have a history of involvement in the political process: they do not appear only when something is wanted from a legislator. It is also important to work in groups such as the CHESS organization and then form linkages and coalitions with other groups -- groups of persons with disabilities, providers of services and community groups-at-large. Have you very actively sought to include among your membership disabled state employees who are major decision-makers within state agencies? What ongoing relationships have you developed with the affirmative action council, with your respective bargaining units and other major forces within the state? Have you formed a chapter of disabled state employees who work in New York City?

We must coalesce and speak with one unified voice in Albany. Experience has shown that inconsistent statements proffered by various disability organizations can only serve to confuse legislators, reduce our credibility and dilute our effectiveness. In fact, while there are many individuals and groups throughout the State of New York who claim to speak for all persons with disabilities, there is not any one group which is representative of any particular class of citizens with disabilities in this state. The Advocate's Office is networking with all disabled persons and their advocates, and we are eager to work with CHESS and all others in seeking every means possible, within budgetary limitations, to achieve the goal set for every citizen with a disability -- full access to the right to participate in the flow of daily community life.

\*(Editor's note: As of August 1, 1983, the governor's program bill broadening the definition of person with disability in the Human Rights and Civil Rights Laws was awaiting the

governor's signature into law, while, at the same time, the Job Training Partnership Act (JTPA) state plan and a new proposal on implementation of the much strengthened executive order on affirmative action, which was signed by Governor Cuomo in February 1983, were about to be promulgated. Both of these contain strong provisions for the employment and training of persons with disabilities).

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\*\*\*Comments made to the Legislative Forum of the New York City Mayor's Office for the Handicapped, March 19, 1983, New York City

As systems advocates, we in the Advocate's Office have worked with state agencies that have statutory responsibilities for service provision, community service providers and persons with disabilities to assure that the unmet needs of persons with disabilities are addressed in a responsive and fiscally responsible fashion. In carrying out our responsibilities as systems advocates, one of our tasks is to prepare a legislative package for submission to the Governor's Office for approval.

Before I describe the processes by which the Advocate's Office currently devises its annual legislative process, it seems appropriate to describe, however briefly, some background information on how a legislative proposal becomes law, including the processes by which the state agency's legislative proposals are introduced into the State Legislature.

I have often said in other forums that the past two years have been an education the likes of which I could never conceive. Dating back to the last 1940's I had periodically gone to Albany to testify on bills of interest and even drafted a few myself. What I never understood was that the day-long forays in the Capitol to spout my "words of wisdom" really had nothing to do with the eventual passage or rejection of a piece of legislation for which I was advocating -- except perhaps as a spoiler. For each of the over 2,000 bills introduced



into the State Legislature pertaining to disability issues each year, there are those who work against passage of these bills. More importantly, the advocates for the bills do not coordinate their efforts. Frequently, such advocates come to the legislature in the same week, even on the same day. These advocates meet personally with the leadership to advocate for the same concept -- but each uses a different vocabulary. This confuses legislators and lends credibility to those in opposition to the proposed legislation.

In seeing a bill which is before the legislature through to passage, regardless of the number of sponsors in each house, it is necessary to know who is in opposition and why they are in opposition. It is equally critical to understand the purposes for which the proposed legislation is introduced. It is also essential to negotiate with those in opposition. Frequently, such negotiation reveals that opposition may be directed against a clause or a provision which the advocates of the bill do not deem critical. In other cases, education, reason and conciliation are necessary. There are cases where responses are not available to disprove adamant opposition. In such instances, it is often apparent that necessary legislation will, in the long run, have a better chance of enactment if introduction of such legislation is delayed until adequate documentation of the facts is available.

Usually, people think of legislation around December or January when the legislature begins its annual session. For an agency of state government, the timetable is very different. Most state agencies have conceptualized their legislative package for the next legislative session by late August or early in September preceding the legislature's convening in January. Depending on the instructions of the Governor's Office, the concepts of each legislative package must be submitted between mid-September and late October of each year. Shortly after these ideas for legislation are submitted to the Governor's Office, the agency is then instructed to draft legislation on those concepts which seem acceptable within two weeks to a month. These draft bills, together with memoranda of support or justification, are sent to the governor's counsel who then forwards them to every other state agency which

has an interest or a stake in the proposal for their comments. After the Governor's Office receives the comments from the other agencies, the agency proposing legislation receives notification of which bills are acceptable for submission. At the onset of the legislative session, the Governor's Office sends the vast majority of acceptable bills to the leadership in both houses of the legislature for sponsorship. A select few of these are designated as governor's program bills, which means that they receive special attention both from the Governor's Office and from at least the branch of the legislature which is of the same party. It has been noted that agencies' legislative proposals which do not survive this process often surface again in the legislature.

For the last two years, the Advocate's Office has endeavored to be true to our mission as systems advocates and has tried to serve as a broker in the legislative process. We have submitted a very limited and discrete legislative package to the Governor's Office and then devoted our best efforts not only to enactment of our own proposals, but also to approval of meritorious proposals from other sources.

Legislation is a year-round endeavor, and not merely a seasonal undertaking. Constant dialogue is maintained with members and staff of not only Assemblyman Hevesi's committee and Senator Flynn's task force, but also with other appropriate legislators. Based upon this constant feedback, the Advocate's Office uses five criteria to decide what proposals to submit.

1. Proposals included in our package are not disability-specific. That is, proposals selected will work for the common good of persons with all types of disabilities in New York State.
2. Proposals must not fall explicitly within the scope of responsibility of any other agency. In the event that they do, the Advocate's Office will work with the other state agency to encourage them to propose the needed legislation. For example, the International Year of Disabled Persons Commission recommended that discrimination against persons with disabilities should be prohibited in the provision of all types of insurance. While the Advo-

cate's Office would play an active role in negotiating and implementing such an initiative, the Insurance Department would properly be the lead agency in any such initiative.

3. Proposals must be consistent with the recommendations of the New York State Commission on International Year of Disabled Persons.
4. Proposals must reflect the priorities identified by persons with disabilities as articulated through such vehicles as the legislative workshop sponsored by the Advocate's Office in 1981 and 1982, our own information and referral system, statewide meetings and general feedback from state agencies, providers and citizens with disabilities.
5. The proposals selected must be affordable and have a reasonable chance of being enacted.

Within these guidelines, my office prepared and submitted a package of five proposals to the Governor's Office for review.

1. We proposed to revise the definition of "disability" in the Human Rights Law provisions of the Executive Law, which is now cross-referenced in the Civil Rights Law, to make the scope of protection offered under state law consistent with that afforded under Section 504. This proposal has been approved and sent to the legislature as a governor's program bill, a designation which assures introduction in the legislature and special consideration and support by the Governor's Office. The concept for this legislation originated among persons with disabilities from all parts of the state. From my earliest contacts in 1981 through our 1982 legislative workshop, you and your counterparts statewide have repeatedly pointed to the need for New York State law to parallel the provisions of Title V of the federal Rehabilitation Act. Studies have shown the absence of a definition consistent with Section 504 to be the most critical gap in New York State law.
2. We submitted a nondriver identification card proposal, which has been withdrawn in deference to a similar pro-

- posals submitted by the Department of Motor Vehicles.
3. We submitted a proposal similar to a 1982 governor's program bill to require affirmative action for women, minorities and persons with disabilities in state and state-assisted contracts. This proposal is still under review by the governor's counsel.
  4. We proposed to authorize localities and school districts to grant persons with physical disabilities a real property tax exemption to the extent of any increase in assessed valuation based upon an improvement to facilitate accessibility. (Editor's note: Chapter 200 of the Laws of 1983).
  5. We proposed to require the President of the Civil Service Commission to study and make recommendations regarding the prompt delivery of rehabilitation services to state employees who become disabled. This proposal -- which we viewed as a pilot study for later implementation on a statewide basis -- was not approved for introduction, but is currently under review by the governor for administrative implementation.

As you can see, our package is limited, both in number and scope, by the five criteria which I outlined previously. As I noted however, there are any number of other proposals -- outside of our own package -- for which we will work as hard as our own proposals during the session. Included among these proposals are early intervention and prevention, nondriver identification and transitional funding for persons who are "aging out" of existing service-delivery systems. (Editor's note: Chapter 570 of the Laws of 1983.)

The legislative process is complex and is often perceived as painfully inadequate in responding to the needs of citizens with disabilities. My office, like the Mayor's Office, seeks to suggest reasonable avenues of resolution to legislators who are constantly bombarded by a myriad of constituent entities, all of whom have compiled legislative wish lists. Too frequently we have noticed that the wish lists from each segmented group, either of persons with disabilities or service providers, have little or no chance of passage as individual pieces of legislation. If, however, proponents could network



together on a unified proposal, each individual need would more likely be met. For example, adaptive equipment is adaptive equipment.

It should be noted that passage of laws -- regardless of their merit -- does not necessarily accomplish the intended goal. The existing structure of state versus local government requires continual monitoring and advocacy for enforcement on the local level. Statewide, this has been the experience with both handicapped parking and polling-place accessibility laws -- to name two. Locally, you are aware of another attempt to ignore what the laws of this state clearly prescribe.

For the next two years, it is doubtful that any major legislation which is not lifesaving or carries a large budgetary impact will stand much of a chance for passage. This affords a splendid opportunity to those concerned with disability issues. There are pieces of pending legislation which are essential but which fail to get out of committee in one house or another for years. In their present form, they may never be sent to the governor for approval. However, if the objectives of such legislation could be identified and networking could occur among all statewide groups who have similar -- not identical but similar -- needs, it is foreseeable that these issues can be resolved. Only by working together to identify common, limited goals and the priorities to attain them can we assure that our efforts will be awarded by laws on the books.

## Accessibility through Awareness

\*\*\*Openings remarks on Restaurant Accessibility, Turf Inn,  
February 9, 1983, Albany

As I was getting dressed, for some reason I thought of an incident from childhood -- the November day when my father took me in for a hot chocolate at the automat after a long day in the cold. For those of you who are too young to remember, prior to World War II there was a chain of cafeterias, especially in New York City, which were automated. You put your money in, pressed the button and got what you wanted seemingly without the intervention of another human being.

As the culmination to this cold, damp afternoon, my father took his severely and multiply disabled daughter in for a hot chocolate. He took me to the table, undressed me, sat me in the chair and went to get the refreshments. When he returned, a man at an adjacent table loudly said to him, "Why in the hell don't you keep your dirty laundry at home? Why do you have to make people nauseous by bringing that kid out in public?"

In the last two decades as I traveled around this country, what has been most remarkable is the emerging visibility of persons with disabilities, with or without other family members. You see them in Yosemite. You see them in the Ever-

glades, along the Pacific beaches and viewing Mount Rushmore. You see them in Denver, in Chicago, in Houston, in restaurants, theaters, museums and churches. This increased visibility in my lifetime has been truly remarkable, but it is not yet what it should be.

The Turf Inn realized several years ago the important contribution people with disabilities have made to this state and country. The Turf began making its facilities more accessible and usable by disabled people. They also began a comprehensive employment program for hiring workers with disabilities especially in the food services area. The director of food services, Lonny Smith, was sponsored by my office for the 1982 President's Committee on Employment of the Handicapped Employer of the Year Award.

As an outgrowth of its concern and commitment to making its facilities available for use by all people, the Turf initiated a renovation project to make its environment more barrier-free. These changes were made so that persons with disabilities, the aging, the businessperson who doesn't consider him/herself disabled, but may have a heart condition, and many other people will use this environment more frequently. The Turf Inn realizes that not only is hiring disabled workers a good business practice, having accessible facilities also demonstrates good business sense and community concern. Persons with disabilities are consumers too. I am pleased that the Turf Inn recognized disabled persons as valuable customers. The efforts of the Turf Inn must be recognized, applauded and reinforced.

Throughout the years of my clinical training, the major professors preached that the real job of a clinician in rehabilitative services is to work hard enough to put himself or herself out of business.

We, the service providers and the advocates for persons with disabilities, have so often forgotten that admonishment. Within today's realities, it is the real world of business and industry that will provide the initiatives for ultimate resolutions of issues related to disabilities. We must learn to support business and industry in these efforts. We can begin by recognizing that we, the advocates, do not call meetings and

do not use facilities into which persons with disabilities cannot enter. All events conducted by our organizations, whether formal or informal, business oriented or social, must be held in barrier-free environments, regardless of whether any person who needs such an environment to gain entry is expected to be present. That is our responsibility as advocates. It also is what we can do now to achieve full integration of persons with disabilities into the daily life of the community.

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\*\*\*Speech to Upper Hudson Library Federation, February 17 and 22, 1983, Albany and Binghamton

Perhaps the freakiest part of my life is my relationship to books and libraries. My job applications always list reading as a hobby because I am, and have been for over one-half a century, an avid reader. For my bachelor's degree, I had minor credits in English, only because I kept taking my electives in contemporary literature, Beowulf and other literary courses.

I have been reading poetry since I was three years old and can, to this day, recite practically all of the "Child's Garden of Verses."

I read my first novel for pleasure at the age of 10 (I was embarrassed into it by my father). It was a book called "Poor Little Rich Girl" -- a plagiarism of "Daddy-Long-Legs." I immediately fell in love with reading -- the fantasy, the escape from reality into another world.

Then I discovered libraries -- a place where I could get all the books that I wanted. I shall never forget my first trip to the public library in Brooklyn. The anticipation of that Saturday afternoon was tremendous because my father had promised on Monday evening that six days hence he would take me to the big library where I could get my own card. It was a long walk, much too long at that time for me to go alone. I realized this and was disappointed. When I got there



my disappointment grew. First, there was a long flight of stairs which I could never make on my own. My father carried me up. And then there was the forbidding quiet.

I shall never forget the austere lady who took one look at this multiply handicapped child and lead her over to the picture books, not quite sure whether any book that she gave me would survive the drooling and shaky hands.

But after the first hour, when I proved to her that I could read and after my father insisted that I be given as much freedom of choice as possible, she reluctantly let me check out six books. The next week it was ten. I was through that children's section (with the exception of the "Honey Bunch" series which I could not stand) in no time.

Many years have passed since then. I have done many things in my life. In college, as a law student, as a vocational counselor, special educator, speech pathologist, supervisor, administrator and so forth. I have worked with all types of disabilities and all ages in a wide variety of service models. The one constant throughout my lifespan is my love of books and my adventures in libraries throughout the world.

Did you know that to a person with a disability, even the most nonverbal child, a book is a precious thing -- as if it is their symbol of normalcy and security? I can remember when I was first approached by the Library of Congress about 12 years ago. They were considering making talking books available to severely disabled children and adults who were not blind or visually handicapped. I remember thinking long and hard about this. On the one hand this seemed like a boon for persons with disabilities such as physical limitations and those with visual/perceptual deficits which markedly affect reading abilities. It might also provide a vehicle to overcome the failure of educators to teach the child with disabilities to read adequately in the name of "specialty." Yet, the symbol of holding a book and turning the pages and what doing this means to a person with a disability could not be denied. Watching the most profoundly retarded child or adolescent lovingly turn the pages often reminds me of seeing my 14-month-old nephew accurately read Mother Goose while holding the book upside down. I

could only explain my ambivalence to the personnel from the Library of Congress.

Why do I tell all this at length? Because to me, a library and the books therein can open up the real world to the person with a disability. In so doing, a path is provided which leads such a person from a life of dependency to one of a contributor -- as a wage earner and as a taxpayer -- to the general well being of the entire community.

However, in order for this to happen, certain fundamentals must exist in the environment.

Attitudes -- Was it not a librarian who first said, "Do not judge a book by its cover?" Yet, we in our culture have been so brainwashed against those who look or act differently that we are not aware of the unconscious biases within each of us. Therefore, I cannot overemphasize the importance of each of you developing self-awareness so that you understand what your own hangups are concerning people with disabilities. Rest assured that you have such hangups. I have them too. But if I identify them for myself, I can then avoid them -- minimizing their effect on my communication with others who have disabilities.

It is just as necessary to try to find out the hangups of the person with whom you are trying to communicate. Has there been some specific, negative childhood experience? Is that person a sibling or a relative of a person who is disabled? Is that person disabled and, therefore, through experience of negative attitudes of others, on the defensive by being offensive? What is the person's attitude toward self? The fastidious person -- the person who never appears in public without every hair in place -- is less likely to accept the disabled, or anyone who looks different -- because that person has not completely accepted himself or herself. It is the responsibility of each of us to have this kind of self-awareness -- awareness of our own biases, awareness of what we are seeing and of the reactions and interactions of others.

The third element is that our unconscious biases were developed out of stories we grew to believe from childhood -- myths about the various types of disabilities. I have brought with me today copies of a pamphlet called "What

Makes Disabled People Disabled?" for each of you to take with you. It not only gives a factual synopsis of each of the major disability groups, it also makes you aware of some of the terminology which really should not be used.

Accessibility -- Accessibility for persons who are disabled, infirm or even different means more than a barrier-free environment. When we think of barrier-free environment, architectural accessibility to a building usually comes to mind and we call in the architects and the engineers who give us expensive estimates on what it would cost to remodel a building. The results of expenditures for renovations are oftentimes very beautiful, frequently enhance the value of the building and, on rare occasions, may be very necessary. However, there may be equally utilitarian alternatives.

I have come to believe that no structure should be modified for accessibility without consulting disabled persons. Frequently, such persons can describe slight modifications which can be made either cost-free or at minimal cost. Often you can find labor for such modifications within the Board of Cooperative Educational Services' (BOCES) occupational-educational groups or even some civic groups.

Flexibility is often the key to reasonable accommodations. For example, if a mobility-impaired person wants a certain piece of literature which is kept on the second floor in the reserved room, it seems more reasonable to have him read the book in an accessible general reading room than to pay a couple of hundred thousand dollars to build an elevator to the second floor. By the same token, because one door has been locked as long as anyone could remember and the main desk faces another door, it does not necessarily mean that New York State and the Federal Constitution say that it has to remain so. I am sure that any qualified librarian can think of alternative ways to carry out the intent of a long-established rule and regulation, and if they are needed, initiate ways which can accommodate the eager patron.

Such flexibility, in combination with accessibility, provides another level of service for which there is no term, except perhaps the word "humaneness." Does anyone really know if absolute silence is needed in all parts of the library?

Does anyone realize what a difference it makes to the deaf or hard of hearing if they are greeted by a person who happens to know a few of the average daily signs. Are talking books only for the blind? Have you ever loaned a talking book to a person with a learning disability? Surely, there is sometime during the day or evening when you can help the severely physically handicapped put a record on or look at a book; or better still, include them in a peer group of able-bodied persons on a regular schedule and establish a mutual assistance strategy among all members of the group. Too often, people forget that we with disabilities have to be givers as well as takers. They forget to afford us the opportunity to give to others.

Self-awareness, barrier-free environments and flexibility unlock another dimension of awareness -- the attitudes of others toward persons with disabilities and what each of us can do to create needed change. Throughout history, world literature, which some may argue reflects rather than creates people's attitudes, has dehumanized persons with disabilities. Shakespeare's "King Lear" opens with "And descant on mine own deformities" as if the disability was the cause of all evil in the world. Poor little Tiny Tim only had a slight limp which was no big deal in his ability to function as a human being. Recent examples from current children's literature are even more insidious because they are published in the name of enlightenment. Not only is there outright sexism and racism in the presentation of disabled children, where they have been all but eradicated from contexts with non-disabled peers, but, when present, the functional descriptions of the disability and what the child is able to do in contrast to his peers reinforces all stereotypical myths of the disabled as a worthless, dependent class which, if allowed, takes from the rest of society.

Your awareness, your refusal to order such filth and your open critique of literature which reinforces biases is the best defense that we can muster against the continuing publication of similar garbage.

I cannot repeat too often "Do not judge a book by its cover;" nor judge those who look or act differently by super-



ficial things. Einstein failed third-grade math. Beethoven could not hear. Steinmetz was a hunchback. Hal Prince could not see. Each contributed something to the world only because he was allowed access to the world of the written word.

# Normalization

\*\*\*Speech to Community Residence Administrators, March 16, 1982, Albany

The array of possible services needed by those with developmental disabilities has grown geometrically as deinstitutionalization has been implemented. It seems as community agencies began to deal with a population they had rejected for decades, there was no clear concept of how to achieve the behavioral growth needed by those with severe and profound disabilities. Therefore, they turned to strategies, techniques and disciplines which had failed to resolve these questions in the past.

Today we are faced with extreme fiscal limitations which promise to increase at least through this decade. As money for human services becomes scarcer, the return to large-scale human warehousing will become more of a reality -- unless we change our attitudinal approaches to what we do. This need for attitudinal change is equally applicable to all, whether you are an executive director negotiating funding and site selection; a residential coordinator involved in personnel problems, coverage and equipment procurement; a client case manager; or a direct caretaker.

Normalization theory has existed in the field of developmental disabilities for at least 15 years. Several years ago, in preparing for some in-service teachings, I accidentally revisited "normalization" as a concept. Since then, I have realized that within its conceptual framework lies the key not only to the achievement of programmatic goals, but also the strategies for each of us to implement our individual roles --

whether we be administrators, consultants, supervisors or direct-care staff. And so, today, I would like to present as I have to many groups involved in community residences, the basic tenets of a curriculum for accessing dignity in the lives of those with developmental disabilities, regardless of the severity or multiplicity of their limitations.

Normalization is a word which is used -- in the first instance -- to stand for an attitude with which all of us are expected to do our jobs. You have clients who are classified as severely/profoundly handicapped. Each of you is, as an individual, different. But all of you have some basic needs and wants that are the same: you want to live and work in a pleasant environment; you want some privacy in your daily life; you want respect as a person; you want someone who cares about who you are as a person and how you behave. In other words, you want love and acceptance as someone unique, precious and somehow distinct from the crowd.

"Normalization" means that every individual -- regardless of his station in life or the severity of his handicaps -- has the same wants and needs as you do. It is your responsibility to see that clients not only learn in the best possible environment, but also that they are taught to respect and maintain this environment. Every individual's right to privacy must be protected. Just as you protect your right to privacy, so should you protect the right to privacy of each individual with disabilities and so should you teach them to respect each other's privacy. Each of you has feelings -- you get frustrated, you get angry, you get silly, you are sometimes happy, you cry, you laugh, you curse, you are depressed, you are embarrassed. Sometimes your reactions to these feelings are appropriate; many times they are not. Sometimes you purposely behave inappropriately because someone did not give you the attention you needed when you behaved as you know you should. How do you feel when you have nothing to do and no place to go, or when you want something and don't know what you want? All people, regardless of how they look, how intelligent they are or how able they are to express themselves -- all people -- feel the same way.

Understanding this is fundamental to understanding what normalization is.

In order to understand what is meant by normalization one must understand three of its components -- least restrictive environment, advocacy and quality and flow of life.

One definition of "least restrictive environment" states that: "Services for persons with disabilities, regardless of severity or multiplicity, should be provided to these individuals as close to the mainstream of society as each individual's functioning permits and with the least possible limitation of his human and personal rights. Providing services in this way can be accomplished best when the community provides a complete continuum of services which permits the individual to choose the manner in which his or her needs are to be met."

What this definition, or any other definition, of "least restrictive environment" boils down to is that each individual must live, learn and work in that environment which comes as close to permitting the personal freedoms and responsibilities, which all of us enjoy, to those whom we serve as each such person is capable of handling: the same freedoms and responsibilities as the rest of us. Least restrictive environment also means that the environment in which an individual is living, learning or working must provide training which will prepare that individual to live and function in increasingly less limiting situations.

In the definition of least restrictive environment, it is stated that the individual must be allowed to make the choice of the alternative by which his/her needs are met. "All adults, regardless of severity of handicap, should live in their natural home" is not a factual statement. Maybe some of them should, many should not. Some people should live in their own apartments or homes. Some adults should live in group homes, some in foster- or family-care homes. Some adults should live in institutions. It is up to the adult to participate in the decision-making process of where he should live, where he should work, where he should play, or where he should have sex and with whom. If the service provider and each of its components does not help to: (1) create the availability



of alternatives; (2) train clients in the ability to choose; and/or (3) permit clients to make informed, independent choices, there is not compliance with this policy.

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Regardless of age group, the quality and flow of daily life for the severely/profoundly disabled individual should be of primary concern. The agency serving the developmentally disabled person should be aware of the individual's sleeping habits, waking routine, bathing, shaving and toileting routine, nutritional intake, food preferences, dining skills, leisure-time activities, capacities for normal risk taking, ability to make choices, mode of communication, frustration tolerance, daily routine of living, opportunities for independence, mode of manipulating the environment, behaviors in a broad spectrum of environments, abilities to cope with time delay and changes, concepts and time budgeting, clothing tastes, ability to choose appropriate apparel and countless other daily routine activities. It is necessary to know what activities are habituated and if manner of habituation is conducive or detrimental to further progress. It is also essential to understand what reinforces appropriate behavior and fades negative behavior in that particular individual.

For those of you who are affiliated with community residences, there are some points which first must be understood, regardless of whether the client is in an intermediate care facility for the mentally retarded (ICF/MR), a community residence for so-called higher functioning individuals, a developmental center or his/her natural-family home. Your clients may have many skills, fluent speech and/or general affect and behaviors like yours. It may be difficult to pick them out of a crowd as being different. If they are like other people, we often assume that they have the same experiences and reactions as we do. Conversely, their affect and behaviors may be so aberrant that feelings of fear and repulsion are often projected towards them.

Regardless of where clients fall within this continuum of behavior and/or personal affect, their feelings in response to

given stimuli are the same as yours and mine. What may be different is that they lack the same experiences upon which to base their reactions to such feelings. One of the most important things we all must remember is that in moving them to a community home, we are taking them away from the only security they have ever known. They are afraid because they are going into an unknown situation. Later on, I will speak about the need for a structure. Scheduling and structuring of duties from the outset does much to overcome this fear.

In speaking of the fear and insecurity which your clients may be experiencing, I mentioned the effect of strange environments, but there are certainly other causes. Regardless of what they verbalize about their families, whether they come from a community residence, from a facility, or from the natural home, some clients may perceive themselves as being rejected by their families. Also, regardless of whether they can verbalize it or not, societal rejection is felt. As a result, the individual client devalues himself. The fear of further rejection, the fear of failure, the perception that he/she, or only the retarded make mistakes, is deep-rooted. Of these insecurities, the last -- the misconception of error -- is the easiest to deal with. When you and I make errors, we usually try to correct them ourselves or cover them up so that no one will notice them. To overcome the fear of failure in clients, we have to teach ourselves to change our habits. Instead of hiding our errors, we must exploit them in the presence of our clients. Oftimes we might even purposely make an error to be able to say, "Oh, I goofed. I spilled the water. Here's the paper towel, I'll mop it up. No damage done, everything is just like it was." Learning to accept the fact that you are human, you do make errors, that the world does not stop and people do not think less of you because you made the error, is one of the most valuable lessons that can be taught.

The importance of the fear of failure and its impact on behavior cannot be overemphasized. I remember a former student who was probably of superior intelligence but was creating a behavioral problem every day in the classroom.

After trying many strategies and many management techniques to overcome the severe behavioral problem, it suddenly dawned on me what I was doing wrong. I realized that every behavioral incident was preceded by a comment from me to the effect, "Now, Clint, I will teach you something new;" or, "Clint, I will show you a different way of doing it." Once I had this realization, I taught what I wanted to teach him with an attitude that it was something which he already knew. It was not until he had mastered the concept or the skill that I called his attention to the fact that he now had a new skill. Clint was so afraid of failing that he would do anything to get out of putting himself in a situation where he might fail. Clint's reaction is not at all uncommon.

As with any other group of people, sometimes we assume there is more language integration than actually exists. For example, as I speak to you today, there is a fundamental assumption that you are understanding and absorbing every point I make. This is ridiculous. Learning theory has documented that even a genius cannot absorb every piece of information as fast as it is being spoken.

Because an individual seems highly competent in certain tasks and skills, too often we assume that they comprehend the subtleties of abstract language. Most of us are reluctant to admit what we do not understand, especially if we do not have feelings of confidence in ourselves as persons. So it is with those whose homes will be in community residences. Major difficulties can be avoided if you learn not to assume that the client understands what you are trying to tell him, just because you know he/she is capable of understanding the words which you are using.

By the same token, just because an adult client has limited comprehension does not mean that he is to be spoken to in an infantile manner. As a speech pathologist of some accreditation, I know that language development in the client can best occur through interventions by direct-care staff in the therapeutic environment of the community residence.

For example, the dinner hour should not be just an exercise in eating. It should be a family ritual -- a time when everybody takes turns telling what happened to them during

the day, or bringing up a major problem they were confronted with and opening it up for discussion. Often these discussions will have to be adjourned to the living room to be pursued. You can never be too busy for this. There may be instances when it's necessary to terminate some topics, if you feel that the discussion is reinforcing a problem. You can only judge the given situation at that moment in time.

Such a support system, which the social worker or others assigned to the community residence can assist you with, is vital. Many community residences have a regularly scheduled meeting each evening not only to review the next day's schedule, but mainly to enhance such a therapeutic environment of counseling and support. This type of support counseling gives you an opportunity to work out the frustrations and need for emotional support with the individual client or the group while the problems are still very, very minor.

A final general concept which must be considered in program development for community residence concerns citizenship training. Historically, persons with disabilities have been trained to take from others, they have seldom been required to contribute either to the welfare of an other or to the welfare of the group as a whole. Integrated in your residence's program and daily schedule should be two types of activities, one to develop client independence and the other to learn to contribute to the welfare of those with whom they share their lives. Today's handout includes some suggested techniques -- at their most primitive level -- which suggest an approach to meet these objectives. You may find that the areas discussed approach both these objectives. They also help build feelings of self-confidence and self-worth, as well as the feelings of being a necessary, contributing member of the family constellation living in the community residence.

In the array of possible needed services, the administrator, manager and the supervisor must re-evaluate priorities. If we consider community residential alternatives as experience in living, then we must provide both the opportunity for such experiences and a milieu from which the client can benefit. Too often I fear that our own biases to-



ward those who are severely disabled prevent this priority-setting in a realistic manner. We attempt to give the client what we think the poor unfortunates are missing. We demand nothing from them in return. We fail to meet their needs in a way that encourages them to become acceptable as our co-equals. Unconsciously, are we planting the seeds of a self-fulfilling prophecy for failure? I will submit that, to avoid any such danger, re-examining normalization theory in light of your own life-styles will lead to more realistic, affordable program planning for each of your clients.

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\*\*\*Speech made at Herkimer Community College, April 1, 1982, Herkimer

In preparing for this presentation I was confronted with a dilemma. Also on today's program is a workshop on "Normalization: Its Future in the 80's." Therefore, those of you who chose to attend this workshop may have already had your fill of normalization. Yet, one cannot adequately talk of advocacy without referring to normalization theory.

Normalization is a word which is used to denote an attitude with which all of us are expected to do our jobs. Each of us has biases -- conscious and unconscious -- concerning disabled people. It is as if each of us, from our first social experience, has been so brainwashed into feeling personally threatened by the obvious differences between us until we never see the overriding similarities. Normalization is, therefore, a word used to symbolize our need to change how we approach what we do for and with persons with disabilities.

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As we said at the beginning, much confusion has arisen as to what is advocacy and who are advocates. This is particularly true when we begin to talk about client advocacy. As has already been pointed out, advocacy has been defined as

the formal roles by which any service-delivery system is made more responsive to all the needs of each individual served by that system. Basic to this definition is the concept that the role of the advocate is a specifically assigned, structured responsibility which carries the obligation of manifesting change for the betterment of the individual. It is, therefore, a clearly distinct, autonomous or semi-autonomous role from others found within the human services system, even though others perform job functions which inherently make the service-delivery system more responsive to the individual needs of those for whom they are responsible. For example, the job responsibilities of the clinical director or residential supervisor inherently hold many duties which fall within the general purview of advocacy, i.e., change for betterment. However, unless specifically assigned, such a supervisor cannot be classified as an advocate. This strict definition is due to apparent conflict of interest.

Without belaboring the varying roles of advocacy as a distinct function -- and there are volumes written on this subject -- suffice it here to say that it is imperative that management clarifies these roles for all agency staff. Too often self-appointed "client advocates" get so involved in fighting the system that they fail to meet their responsibilities to prepare the client to function with ever-increasing proficiency within that system.

One must question what is the true role of some self-styled client advocates. Those viewed today as trainers in client advocacy may be more appropriately called facilitators of goal achievement in quality of daily life, self-advocates, or even monitors of specific aspects of the delivery system. If we view advocacy as functioning independently of the system, can we then call a case manager who is employed by the system a client advocate?

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\*\*\*Remarks made at NYS Office of Parks, Recreation and Historic Preservation Conference, April 19, 1982, Kiamesha Lake

When I think of recreation and leisure time activities for persons with disabilities, I cannot help but think of my parents and my childhood. Neither mother nor dad had had any prior contact with a disabled child. As a matter of fact, as the youngest of both families, neither had more than minimal contact with the growth and development of young children. And so, their approach to me was most schizophrenic, especially when it came to areas of recreation.

I had rollerskates before I could walk five steps. I was horseback riding, under instruction, by the age of four and being taught swimming by a master before the age of five. I was tempted to bring with me pictures of me on a golf course at the age of nine; or on the tennis court a year later. Ballet and tap were a part of my weekly routine -- just as were physical, occupational and speech therapy -- because all the girls of my socio-economic class took dancing from the neighborhood dance school. I began going to camp at the age of eight or nine, but these were not camps for the disabled. Sure, I did not do many of these things well. Sure, I was different, and in some aspects, participation in normal recreational activities at the time somehow emphasized my differences.

But it also taught me many strengths. As I gained my own competencies in each of these activities, I came to have confidence in myself as a human being. I would never be a world-renowned equestrian, but I earned my junior lifesaving certificate in swimming. I hated golf and am poor in tennis, but it was my choice not to participate. I could not keep up with the chorus lines in the dancing recitals, so I always had solos. Boy, was that ego building! At one point during adolescence, I won a campaign to go to a camp for disabled girls and women. Later, I became a camp staff member and I began learning a lesson that has remained with me throughout my lifetime of involvement in recreational and leisure-time programs for individuals with disabilities.

This camp was sponsored by a group of "good ladies" who for years collected their pennies to build a pool at the camp site. Finally, they felt they had enough money and went to a world-renowned pool architect and told him about their dream of a pool for the "poor little crippled girls." He designed a pool. It was a perfect circle. It was 18 inches deep around the rim and was 20 feet in diameter. At the nucleus of the perfect circle, the depth was four feet by nine-and-one-half inches. Not a single camper could be taught to swim in this "birdbath." Today, the camp exists for all kinds of handicapped children. I understand that for at least the last 20 years they have a real swimming pool.

I tell this favorite birdbath story as an extreme illustration of something that you and I may have been doing for many years. When the Kennedys first established Special Olympics, it was good publicity for a much-needed activity. The education which occurs because of Special Olympics can never be overemphasized. Now we have to review what we are doing. For example, after an individual wins a blue ribbon two or three times in the same event, shouldn't he be urged to progress toward a wider arena? Isn't he now ready to use his abilities in the mainstream? Special Olympics and all major sports for the physically disabled or other similar, segregated athletic events are only the beginning of the commitment to mainstream the individual into normal recreation activities. If we lose sight of this fact when that individual reaches a high level of competency in the activity, we are devaluing the individual to himself and to others.

I have even more trouble with the concept of therapeutic recreation. Recreational activities contribute to the growth and development of the participants. Look at the therapeutic values in jogging, playing racketball, tennis or whatever your thing is. It makes you feel good. It gives you a point of conversation with your friends. It gives you something to do to prevent boredom. It keeps you interested and motivated. It sets you up for some goal achievement that will feed your ego. The nucleus of my hangup about the concepts of therapeutic recreation is that, in practice, my experience has been that therapeutic recreationists try to be just like



occupational, physical and speech therapists and lose sight of the value which existing competencies can contribute to the quality and flow of daily community life.

Too often the result is that the recreationist becomes so burned-out by trying to be a carbon copy of another discipline that they give up -- blaming their failure first on others. My favorite example is that of the senior recreationist whose concept of activity was loading the van with a group of clients and driving out to Montauk Point and back. Since there is nothing to do at Montauk Point, all they did was go to the bathroom and take the two-hour trip back.

Here again a far-out illustration is given to raise your own level of consciousness. The real issue is whether you are contributing your expertise -- what you know better than anybody else -- to the client's ability to function in increasingly less restrictive environments. Is what you are doing for and with that client really increasing his/her self-esteem?

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\*\*\*Speech made to the Capital District Wheelchair Sports Exposition, June 12, 1982, Albany

The importance of this first Capital District Wheelchair Sports Exposition is manifold. Although Americans have long believed that participation in competitive sports is preparation for competitiveness in life, little has been done to show the world that persons with physical disabilities can and should participate in this essential aspect of education.

Our nation has become sports happy. Watching professional teams on television is not a sufficient addiction. Today, most people are jogging, playing tennis, bowling, taking karate, judo or aerobic dancing lessons, and who know what else. No longer can those with physical disabilities be relegated only to swimming and horseback riding. The importance of physical fitness for all people is proven. Are we people too?

Most significantly from the viewpoint of the Advocate's Office, the more the general public sees persons with disabilities doing what they would like to do -- and doing it exceedingly well, the sooner we will achieve the goal which Governor Carey has set -- namely, that all persons with disabilities should be fully integrated into the daily life of the community.

It, therefore, gives me great pleasure to present you with the proclamation which Governor Carey has issued in recognition of this auspicious day.

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\*\*\*Speech to the Coalition on Sexuality and Disability, Inc.,  
June 17, 1982, New York City

For some months I have been traveling around this state giving the reason why I walk differently, talk differently and have unpredictable use of my hands. By strict definition of the word, I really am a freak -- in that I have a very rare type of cerebral palsy.

I was told by a neurologist, when I was 13 -- which was, and is, much too young for this knowledge -- that I could never survive a pregnancy. At the age of 28 I decided to marry. My family insisted that I go to one of the most renowned pair of gynecologists/marriage counselors in this city for birth control instruction. (This was in the days before the Pill.) I was given a diaphragm. I tried to explain that, given the unpredictable use of my hands, this device would provide no protection. Despite the fact that I was a lawyer and by that time had at least one other graduate degree, no one listened to me.

Twelve months later I found that I was pregnant. I went to the most renowned gynecologist/obstetrician in the state in which I was then residing and explained to him -- or at least tried to -- why, neurologically, the pregnancy had to be terminated. He telephoned three famous specialists in cerebral palsy, all of whom knew me but none of whom had ever

examined me. Upon their advice, he refused to terminate the pregnancy.

That was back in 1952 when, in New York State, pregnancies could be terminated only for medical reasons and upon the certification of three physicians. I came back to New York and entered one of its medical centers where my attending medical staff consisted of five famous specialists. It was documented that even staying in bed for the entire period would only result in my death before the child was born, and the pregnancy was terminated.

I began with this very personal story tonight because it seems to me that it is a perfect illustration of what the Coalition on Sexuality and Disability is all about. Much has been written about gynecologists' general insensitivity to their female patients. Jokes about "50 fingers" have been around for years. In my generation at least, much was also said about physicians general inattentiveness toward their patients.

For example, I remember the time I developed an ulcer, which coincidentally was at the same time that I was trying to learn to drive. I went to my excellent internist and had a whole series of tests. During the interview, I reminded him of my hypoglycemia. He ignored this reminder when prescribing the diet for my ulcer, an oversight I was unaware of until I passed out at the wheel of the car.

These are horror stories which occasionally happen. After all, physicians are human too. However, in speaking of routine medical care for people with disabilities, there are other factors which must be considered, particularly for those with physical impairments. It has been said that our bodies are the vessels of our personalities. When an individual knows that they have a defective vessel, it is too easy for them to devalue themselves as human beings. This lack of self-respect is reinforced, especially in areas of sexuality, by parents, classmates and everyone else with whom they make contact. I have often said that I have no personal knowledge of sexual harassment because it seems to me that even the worst male chauvinist does not classify me as a woman because of my severe disability. To be frank, I am not certain

that is completely true. Somehow I believe that I may have been so preoccupied with overcoming other aspects of bias that I did not recognize preliminary overtures and, therefore, they were unconsciously rebuffed.

Be that as it may, the point here is that when the person with a disability goes to the physician, the patient often has inadequate feelings of self. The physician may have the same biases toward the disabled as are common among the general public and the combination of the two, interacting with the physician's routine attitudes toward the patient, creates a situation that is ever more disastrous than it is for those patients who have no disability.

One additional point, which may be obvious to some, is that sexuality and sex are not synonymous. One who practices celibacy can be sexually healthy. Sexuality is more how you view yourself as a human being and the way you look upon all your attributes as an integrated whole. I don't particularly like having a disability. I also prefer blue eyes and blond hair. Even when I was young, I never wished that I had been born without a disability. What I did wish was that I had been born a male, because I thought that men with disabilities had more choices in life than women. I now enjoy being a woman. But then, I have learned to like me.

When Joanna called me about this occasion, I could not help remembering the first statewide conference on sexuality and disability which United Cerebral Palsy of New York State held in 1972. Issues presented then remain unresolved today. There is an ever-growing media emphasis on sex. Everyone is made to feel that without direct involvement life isn't worth living. I can remember that as an adolescent I felt extremely isolated -- that everyone else was half of a pair, like on Noah's Ark. Recently, a group of women friends and I, all of whom have been widowed or divorced for several years, had a discussion on marriage.

We found that we were in total agreement. We enjoy the company of men, we enjoyed intercourse when we had it, but not one of us wants to remarry. As one woman in the group said, "My sexuality has matured to the point where I am unwilling to adjust my independence to the constant



needs of another person." How does this evolution of personality occur?

Those of you who know me probably are trembling at the prospect of my three-hour diatribe on the subject. Rest easy! May I give only a few highlights? Sexuality, as part of human personality, begins at birth. It is an indivisible part of how individuals feel about themselves, their bodies, their appearances and their perceptions of how others respond to their innate needs for love and respect.

It is well documented in human growth and development that the child increases his knowledge of self and relationships to others by different strategies at different ages. Masturbation and homosexuality are normal activities at particular levels of emotional growth, regardless of all pretenses to the contrary. As a matter of fact, either act can occur without any sexual overtones. For example, among the profoundly retarded and the profoundly multiply masturbated may be the one act completely under their control through which they can with certainty experience good feelings, feelings of pleasure. Such resultant feelings are sensorial, not sexual. It is only in the warped minds of the viewer that any other meaning can be applied.

As we all know, Sigmund Freud did his work among women with hysteria who were reared in the repressive Victorian Age when human personality was prevented from healthy development. By removing his teachings from their original context, his disciples so grossly distorted his contributions that for a time the world believed that Freud dwelt only on sex, whereas I believe that was not what he was referring to at all.

The individuality of each human personality is a very real thing which demands understanding and respect for others. We must learn that there is no "right" or "wrong" in human behavior, except when it affects others. In community living -- in being a part of a group -- to have what each of us needs in friendships and relationships with others, each person must learn to discipline and channel his behaviors, not because they are "wrong" -- but because they may be inappropriate under given circumstances and/or at given times.

These are but a few of the major concepts which persons with disabilities, their families and the professionals who work with them must learn are equally applicable to all individuals, regardless of whether or not they have a disability.

It seems to me that this is the essential purpose of the Coalition on Sexuality and Disability -- to coalesce persons with disabilities, parents, physicians and other professionals to discover ways in which people with disabilities can learn to like and respect themselves and, in the process, teach professionals what they need to know in working toward meeting this goal.

## Early Intervention

\*\*\*Speech made at Fordham University on Access to Dignity  
-- Early Intervention Programs, March 13, 1982, New York  
City

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As soon as a child enters a program, attention must be placed on his rightful citizenry in his family group. Parenting is much more important than overcoming assessed physical deficits. As a matter of fact, those deficits cannot be ameliorated toward normalization if the parenting skills are not enhanced. Regardless of severity or type of disability, there are variances in the child's environment at different ages and stages.

The infant, the child under 12 months of age, is home-centered and the delivery system should be home-based and home-centered. This means the focus must be on the total family group, not on the child's disability. It also means that whoever is working with the family must understand family members' needs and biases and design interventions that relate to integrating the disabled child into the family group.

Thirty years ago, minority group families were acclaimed for accepting disability and integrating the child within the family group (sometimes too much so because they did not seek help, even when it was accessible within their frame of reference). This is no longer true; nor are services necessarily accessible within the family's purview, despite the growth of

programs. Then too, I suspect that, as levels of aspiration rise, as survival becomes more complex, parents of infants labeled disabled -- regardless of racial or economic status -- are confronted with the same dilemmas.

Historically, when referring to the parent-child relationship in families of developmentally disabled children, the term "rejection" has been used with astounding frequency. Parental rejection of a child is, in reality, a rarity. It probably occurs only in instances when one or both the parents cannot accept themselves as a viable human being.

What parents do reject, consciously and unconsciously, are concepts, ideas with which they cannot cope. Each of us, when faced with a problem -- especially problems with which we are totally unfamiliar and/or about which we have certain preconceived biases -- immediately seeks simplistic, recipe-like resolutions. When parents bear a defective child, they must face the demise of dreams and aspirations, which may have been nurtured since childhood, related to ego fulfillment through the lives of future offspring. Simultaneously, they must seek a concrete answer to the question "why me?"

This bereavement or grief process is so well recognized in the literature that its course has been clearly defined. The parent is not able to cope with the child as a child until he/she has progressed through the various levels of grief. There is a direct relationship between the current status of each parent's progress in the grief process and the quality of parental bonding to the child. It, therefore, seems that early intervention programs should focus upon these areas of concern.

It must be recognized, too, that the realities of childbearing and early childrearing are at variance with everyone's adolescent dreams. For example, the reality of changing a dirty diaper in the middle of a meal has no place in earlier fantasies about the beauties of motherhood. The need to reconcile the reality with the dream places an emotional strain on each parent, let alone their interactions with one another. If this is true of the average parent whose infant is not in difficulty, consider what parents who know they have a defective child must experience -- or parents who may not yet know -- but who are witnessing their child's aberrant



behaviors in eating and sleeping patterns, primitive relationships with the environment, and countless other intangibles.

Those of you who are familiar with the current crises in teenage pregnancies realize that this gap between fantasy and reality is apparent among other groups of parents. The point here is that the greatest need of the young child with disabilities is that of good parenting skills, rather than expertise in therapeutic approaches to the disability itself. If we can refocus what we do for the child and the family on this simple fact, the child with disabilities can be integrated as a participating, contributing member of the group. Such family citizenship is a required prologue to functioning in the increasingly less restrictive environments of school, work and the community-at-large.

Individual means of coping with this emotional stress vary greatly. The parent who calmly, matter-of-factly answers all the intake questions may be under considerably greater emotional stress than the parent who weeps. It also must be remembered that the intake process itself forces the parent to recount in considerable detail repeated instances of self-perceived failure. (Incidentally, the parents go through this experience again at the times of initial psychological, initial medical and perhaps to a lesser degree, other evaluative or teacher-therapist conferences.) Hostility, denial, projection and every other psychological coping mechanism are normal behavior, under the circumstances. It is a wonder that most parents react as positively as they do. One is impelled to muse about how each of us would react under similar circumstances.

It should be quite clear by now that what the parent is initially requesting can be summarized as:

1. "Do something now to my child that will enable me to cope."
2. "Explain to me in words I can understand and believe what is wrong with my child."
3. "Give me hope -- not that my child will be cured -- but that I can look forward to the time when I can really accept my child as he is -- and that people I love will accept my child."

In formulating the responses to these requests, several facts are fundamental:

1. The primary parent, and parent surrogate, in the case of working parents, are the principal clients of the agency. Whatever non-medical, direct interventions with the child are needed, the primary caretaker, and not the agency staff, are to provide them.
2. Such intervention must be designed to be carried out within the framework of the family milieu. Any home program which places additional burdens on the parent and/or separates the child from the family group reacts negatively upon that child's personality growth and development. (What we do-gooders forget too often in working with the child and his family, is that the child, regardless of the severity and multiplicity of his disabilities, must be trained to give to others and to realize that the world doesn't center about his needs. Too many of the traditional techniques and attitudes towards the disabled youngster reinforce concepts of self-centeredness which lead toward later social and economic rejection.)
3. The agency should provide babysitting so that husband and wife can have time for each other or so that the parental attention to the other siblings can be equalized with the attention which the mother must pay to the severely disabled child. These are viable components of a delivery system aimed at least restrictive environments and normalization.
4. It is advised that the child be taught skills which will relieve the caretaking burden and in which the parent can take real pride, regardless of the order of such skills in the developmental process. For example, I caused infants with developmental disabilities to be toilet trained before twelve months of age, by a biological conditioning process. This not only avoided all the emotional negatives that the literature ascribes to early toilet training, it also, more importantly perhaps, permitted the parents to boast among their peer group with a real sense of accomplishment. By the same token, I remember a black woman who, three decades ago, bought her four month old,

fatherless grandson a walker. At age five months he was walking, creating his own "infant stimulation" program. In a similar context, a staff member of mine taught primary caretakers -- mothers or others -- to handle and play with the infant using neurological-facilitation techniques. The babies with Down's syndrome were sitting by six months of age and standing at seven months. Today they are all successfully mainstreamed at the junior high school level or above. More importantly, they are nice people to know.

5. The toddler who is not disabled begins expanding his environment soon after his first birthday. Outdoor play without adult presence is permitted. Parallel play with other toddlers is begun. Exploring the environment increases. All of these add to risk-taking. The nondisabled toddler gets into more things and gets injured more frequently. This is part of the normalization process for every child.

In contrast, what do we do with the youngster with a disability? We tend to over-protect our children. We tend to prevent harm. If you don't take a risk, you don't learn anything. Such risk-taking implies not only preplanning for consequences, but also the incorporation of self-assertiveness and self-advocacy training in every program curriculum. In a very real sense, service providers must begin to view themselves not as client advocates, but as trainers of client advocates, thus acknowledging the only true client advocates are the recipients of their services. In this training role, service providers must learn how to train people for viable advocacy against itself as an established agency.

Most of you here today are thinking that, while what I've accomplished is remarkable, it has little to do with the students you're concerned about. I am obviously intelligent. I come from a background geared toward achievement and upward mobility -- one which fostered all the right American social values. There are some who may even think that the stock which emigrated from mid-Europe or Ireland in my grandmothers' era differs generically from today's emigrants from the Caribbean and elsewhere.

In addition, while I am obviously intelligent, their intelligence is limited. They have major behavioral problems, while I know how to behave. That's the whole point of today's session. We are the same. Times are different. As I already tried to tell you, people looked upon me when I was young the same way people in the community look upon clients. The difference is that I was lucky to be born to parents who, perhaps through their own ignorance and false pride accidentally developed a formula for childrearing which allowed me to grow and learn to cope with living in the real world. Today we can no longer afford to squander our resources -- fiscal or human -- to leave such approaches to luck. It is often said that society's rejection of persons with disabilities is founded in the feelings of "There but for the grace of God..." I know that feeling well. It is the forge upon which this workshop on Access to Dignity has been fired.

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\*\*\*Presentation to the Early Childhood Education Council of New York City Annual Conference, March 26, 1983, New York City

For most people in our society, the anticipation of the birth of a child is a most exciting period, full of dreams, aspirations and anticipation. For such persons, the advent of a child with a handicapping condition is not only a profound disappointment, it is an experience akin to the death of a loved one. According to the literature, parents go through the same stages of the grief process that one experiences after the loss of a close relative. Support to the parent through this process is considered essential to the future growth and development of the child. Without such support, the parent or parents may never progress through all the stages of grief. Their attitude toward the child and his/her role within the family group may be arrested at primitive levels of bereavement.



More than a decade ago there was a three-year national collaborative study on infants with handicapping conditions. The findings included:

1. Rejection, as it is defined in psychology, is relatively uncommon among parents of disabled children. (The exception here may be the parent who did not want any children in the first place.)
2. Early childhood (ages 0 to 3) may encompass three or more distinct stages of development, each requiring different strategies.
3. During the early stage, roughly 0 to 9 months, the parent who is the primary caretaker is extremely willing, and even seeks, to listen to suggestions from the support system. However, if such a support system is unavailable or unresponsive and the parent is left to develop strategies by trial and error, the willingness disappears as the self-found strategies become habituated.
4. Most clinicians speak to, but do not communicate with, the parent, even when they are making concerted efforts at such communications. Helen Bee Douglas of the University of Washington did both video and voice tapes at many of the centers participating in a project as part of a staff-training component which repeatedly illustrated this.
5. Both the young child (infant) and the parent have major difficulty in coping with support from more than one or two sources at the same time. The project, therefore, gave rise to a concept that the parent (caretaker) would be the primary intervener with the infant under nine months, and an individual on the clinical team would be the primary intervener with the parent.
6. In matters like diagnoses and habilitative prescription, the evidence indicated that these matters must first be presented to the parent by the physician. Immediately thereafter, there should be follow-up by the parent's primary intervener, not only to ensure that there is comprehension of what the physician said, but also to explore the parental feelings about what was said to prevent deterioration in attitudes.

7. At least one center reports that between the ages of three months and six months, caretaker parents tend to stop talking to the infants during critical periods in the daily routine. (This finding has also been reported elsewhere by Lawrence Taft, M.D., and Reginald Luria, M.D.) The importance of this report is that experimental psychologists have hallmarked this age as critical to perceptual, language and cognitive development
8. Children with handicapping conditions are not always born to stable marriages, nor do they always have emotionally stable individuals as parents. Even where the marriage and the parents are considered stable, the incidence of having a handicapped child places extraordinary strain on parents. The maintenance of a healthy family entity is critical to the infants growth and development, as well as to the prevention of further handicapping conditions, even if such maintenance may temporarily sacrifice clinically prescribed therapeutic interventions. However, the necessity of such choice is rare, provided that the strategies for prescribed interventions are adapted to the dynamics of the individual family group.

While the importance of universal preschool for children with handicapping conditions cannot be overemphasized, it is equally critical that supportive services begin for the families of the children at the earliest possible moment. One of the major barriers to instituting universal early childhood intervention, in my opinion, is the lack of understanding of the true nature of such intervention. While most people think in terms of diagnosis, assessment, medical and rehabilitative services, these may not be the most critical factors in working with infants and toddlers with disabilities and their families.

As the title of our agency brochure "What Makes Disabled People Disabled?" implies, the most severe handicaps which those with disabilities experience originate with the attitudinal biases towards persons with disabilities. Such attitudinal biases too frequently lead to negative interactions between the person with the disability and the society in which he or she comes in contact.

I support early intervention for infants and toddlers with disabilities -- not primarily for their rehabilitative value -- but as a means for overcoming biases and encouraging normal growth and development of the child. That child, like any other child, must be an accepted member of a family-like group. He must be taught to give to, as well as to take from, the group. He must be taught his responsibilities as a person towards the group. He must be permitted to exercise these responsibilities.

Quite frankly, society can no longer afford the results of the luxury of our biases. The primary result of such biases is that persons with disabilities, for the most part, remain dependent and therefore an economic drain on public funds. Therefore, it seems that the best way to overcome the self-fulfilling prophecies of attitudinal biases against persons with disabilities is to nip them in the bud from the moment that the child is born -- to treat the initial psychological trauma on the family so that they will treat the child with a disability as they treat the child with blue eyes born to a brown-eyed family. Neither the fact of disability nor the color of the eyes should dramatically prescribe or change the basic needs of childhood.

It has been demonstrated that such support services can best be given by the generic family or community worker, provided there are three things available to that worker:

1. Training, particularly sensitivity training, so that the worker may come to know his or her own biases towards persons with disabilities. Once these are brought to consciousness, their effect in dealing with others are usually limited.
2. A support system which knows where to find expertise when needed and that also provides someone to talk to when staff frustrations begin to build.
3. An information and referral resource so that when professional help is needed, you can find out where it is available.

# 10

## Rehabilitation

\*\*\*Speech to Advisory Council of Vocational Rehabilitation,  
January 26, 1982, Albany

All of us realize that it is unusual for a member of the Commissioner's Council on Vocational Rehabilitation to get up and make a speech. I thank you for your indulgence, and since I have the podium, I would like to take this opportunity to list some areas of long-range concern:

1. The absence of a visible, statewide effort at job development in the private sector that focuses on the initiatives for resolution of issues by industry, labor and business, rather than us "do-gooder, rehab types."
2. The absence of uniform, statewide standards which would be equally applicable to the particular program or services, regardless of what state agency is responsible for the provision and monitoring of such service or what type of a community agency is the direct deliverer of the service, as well as a single, uniform process to monitor adherence to such standards.
3. The lack of clarity in the public's ability to distinguish between sheltered employment as part of the vocational-rehabilitation continuum and sheltered employment as a successful job placement. Existing confusions may lead to "Band-Aid" resolutions -- enacted in response to political pressure -- which will be detrimental to the client, the service provider and the community-at-large.
4. The lack of sufficient coordination among state agencies concerned with delivery of services to citizens with disabilities. For example, when decisions in the human ser-



vices arena are made under the present structure of state government, the concerns of vocational rehabilitation and special education usually are not represented around the conference table; nor, for that matter, are the Departments of Commerce, Labor or Transportation, to name but a few. This is in no way meant to belittle the numerous and valiant efforts that this administration and all of the affected state agencies have made at better coordination. I raise this example only to illustrate that achieving the ultimate goal of having disability issues brought into the mainstream of this state's decision-making process necessitates continuing initiatives in additional areas to promote the comprehensive coordination of efforts.

5. The need for review of the existing model, as well as current practices, in education and vocational rehabilitation. Are there better models, systems and processes through which a greater number of persons with disabilities can more adequately be prepared for current and future competitive employment? If so, what are they, and how can they be implemented in the most fiscally responsible, cost-effective manner? However, apparently unlike the present administration, I do not believe in elimination of existing programs and services, however marginally effective in obtaining new goals they may be, until their more effective replacements are implemented.

I believe that advisory councils such as this should take the initiative to make recommendations concerning such issues.

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\*\*\*Speech made at Helen Hayes Hospital, May 28, 1982, West Haverstraw

I cannot tell you how privileged I feel in participating in this 88th annual honors assembly at Helen Hayes Hospital. As you may know, I've been traveling around this state for about 18 months saying that I am a freaky lady because I

walk differently, talk differently and have unpredictable use of my hands. Obviously, I was born with cerebral palsy, which affected my walking, my talking, my chewing and swallowing, my ability to dress and feed myself, and the way other people treated me. To this day, I cannot write legibly, but I've written several books on speech pathology and special education because I began to learn to type in occupational therapy.

I have had a lifetime of therapies -- physical, occupational and speech. In fact, my first physical therapist began working with me before I was two years old. On my fortieth birthday, I decided enough was enough and removed my name from the speech therapy schedule. In all the years in between, I do not remember any period of my life longer than two weeks when I did not have some therapy, mostly all three of them. That is one reason why I am so happy to share this occasion.

I was a child in the olden days, when the New York State Rehabilitation Hospital at West Haverstraw was not equipped to treat people with cerebral palsy. I well remember the opening of the first cerebral palsy wing and the first classroom teacher, who to this day is a close friend. But that was very long ago. I also remember that, as the director of a Children's Day Rehabilitation Center in upstate New York, it was to Haverstraw -- as we used to call it -- that we sent our children when we wanted expert diagnosis and guidance -- just as my colleagues at the local rehabilitation center referred their physically disabled adult patients. I continued making referrals to this mecca of expertise when I was residential chief of service at Suffolk Developmental Center. We always sent clients to expert staffs struggling with ancient equipment, in even more ancient buildings.

Governor Carey's foresight in recreating this outstanding medical rehabilitation facility into this modern, up-to-date, fully equipped resource has given persons with disabilities and their families -- now and for decades to come -- light and hope for the future. By naming it after Miss Helen Hayes -- a woman whose creativeness, courage, ability to give enjoyment to others and sheer humaneness, represents the best in

each of us -- by calling this facility the Helen Hayes Hospital, he symbolized all of what we dream of achieving here.

To you who are being honored here today, first let me say that I am a little jealous. Never in my life was I told that I had done a good job in therapy -- but then maybe I never deserved such praise. You undoubtedly do. Congratulations. Remember this day with pride. Use it as a tool and as a shield. The very things that brought you this honor today -- hard work, willingness to try over and over, wanting to do it right no matter what, listening and learning and above all doing -- these inner tools are the things that will achieve what you need in the future. No one wants to have a severe disability. Once you are disabled, however, it's like the color of your eyes -- what good does it do to wish that they were another color? And so in the future -- when life gets you down, when nothing goes right and you feel that the world's against you -- remember today. You made it to this honor. You'll make it to all the others in life!

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\*\*\*Speech made to Russell Sage College Physical Therapy Student Conclave, June 19, 1982, Troy

As I thought about today's panel, the first thing that came to mind was that I could not claim to this group that I had cerebral palsy. It would be a breach of faith with the neurologist who reared me. Beginning at about the age of three, he taught me to tell medical and physical therapy students that I have cerebellar hypogenesis, which means that my cerebellum is fragmentary and nonfunctioning. Only my post mortem can verify this hypothesis.

"A rose by any other name..." nevertheless exists. I speak of Dr. Frederick Tilney because he is the reason why I am able to stand, walk and talk to you today. Using the philosophy that he "didn't know what good it would do, but it couldn't hurt," formal physical therapy was begun at eighteen months of age and continued for over 20 years. I

probably know first-hand more modalities than are taught in the schools and post-graduate workshops today.

In the intervening years, I have been simultaneously victimized and enriched by your profession in many ways. I have been a fellow-student, co-worker, a teacher, a practicum supervisor, an employer and a colleague. I have lived through the fads of bracing-no bracing, crawling-no crawling, sand walking, floor sitting, stretching-no stretching, relaxation-no relaxation, and on and on. Every few years, someone comes up with some new approach which sweeps the country as a panacea -- the answer to all movement problems. I was a graduate student when Sister Kenny arrived in this country; the first Bobath article to be published in this country was in a magazine that I edited...and I can go on...

My own clinical training is mainly in speech pathology, and frankly, there was a time when other clinicians called most physical therapists the "push-pull-click-clickers" -- meaning that they viewed human movement as a mechanical problem, and not one of motivation, personality and emotional attitudes.

The practice of physical therapy includes many domains, from the prevention of debucita in the bedridden, through the creation and measurement of prostheses and adaptive equipment, to the most advanced types of ambulation training. Today, I would like to call all these arrays "movement," for the purposes of explaining other points pertinent to today's panel.

Another generality that must be assumed for this purpose is that all physical therapy patients fall into one of two categories: those whose disabilities came after normal movement patterns were habituated, and those who never experienced normal movement. This categorization should be familiar to you, since, in any theoretical study of the mechanics of movement, a basic premise is that it is simpler to rehabilitate the individual who has lost normal movement than it is to habilitate one whose central nervous system and movement patterns have never been intact. There are also psychological bases for arguing the validity of this premise,



and understanding them are perhaps more critical to patient progress.

The person who becomes severely and irreversibly disabled in adulthood not only knows what competencies are missing, but, as able-bodied persons, may have held some biases toward the disabled. Now that they are in this category, they may emotionally exacerbate the extent of their incompetencies as a human being. This has far greater impact on the processes of restoration than is reported in the literature.

It has always seemed to me that for rehabilitation to be effective, the patient has to work through these preconceived biases at the same time as the modalities of physical restoration are occurring; this requires that the therapist have previously worked through unconscious biases toward people with disabilities. I remember when, a number of years ago, I was involved in an intensive program for severe cardio-vascular accidents. Real restoration of functions did not occur until we got the speech flowing at a rate of intelligibility where we could comprehend what the patient was saying about the day the stroke occurred, what lead up to it, what feelings were experienced, and a variety of other details. I well remember how we worked for that day and what extremes we went to to understand what the patient was saying. Although the question of speech intelligibility has not always been involved, similar strategies for release from guilt of bias has been very effective in rehabilitating those with spinal cord injuries.

For those whose disabilities originated prior to habituation of normal movement, there is a very different psychology involved. In the first place, regardless of what the patient verbalizes about wanting to be able to do, there is no real appreciation of the energy or effort involved in doing. Going to the hospital, clinic, or the private physical therapist, even when the physical therapist comes to the home to give treatment, may be perceived as an irrelevant nuisance -- a removal or isolation of the child from where that person wants to be or from the activities perceived as having higher priorities to the individual's concept of self.

It has always seemed to me that people who do not have a disability assume that persons with motor disabilities naturally want to improve -- regardless of the time, effort or other sacrifices to be made in search for this abstraction called progress. "Improvement for improvement's sake" is hogwash of the same category as the statement that "all black people want to be caucasian." This assumption of the nondisabled is based on their own feelings of guilt and biases, probably originating with very human reactions to "There but for the grace of God go I." However, I submit, if these assumptions and their underlying biases did not exist, some of the age-old procedures in physical therapy would not be standard operational procedures today.

I remember once participating in a demonstration on relaxation techniques in cerebral palsy. A famous physical therapist got each of us, in turn, very relaxed and then instructed us to perform an assigned activity. There was no transition between relaxation and performing the activity. Therefore, each of us approached the assigned task in the pattern which we habituated for years, without any thought of carrying over the kinesthesia of "relaxation." Much of what is done today may be of the same caliber. Why haven't universally accepted strategies been developed so that the physical therapist plies the modalities within the person's environment -- whether it be the child out playing with the other kids on the block, or in the classroom doing an eagerly anticipated group activity, or the adult in the workplace? Leaving theoretical rationalization aside, is this absence based on any perceived personal threat to the physical therapist? If so, what is the nature of these threatening perceptions?

These are questions which must someday be faced, because present strategies of individual treatment in segregated rooms may cause emotional problems so severe in nature that not only is progress in movement impeded, but the patient may also engender misperceptions in body image and feelings of self-worth. Another result of this segregation may be found in the reluctance of many physical therapists to specialize in developmental disabilities.

I have never understood why, in instances of severe physical disabilities, particularly those neurological in origin, there has not been a concerted professional effort to bring the professional to where the action is in the daily life of the individual. In isolated situations where I have seen this happen, the professional's and the patient's satisfaction have been so rewarding that I always expected replications all over the place. I am here today as positive evidence of what physical therapy can do, even when the person is born with severe, multiple disabilities. However, in all fairness, I must also point out that it requires years of counseling to overcome the feelings of segregation, uniqueness, incompetency, and feelings of self-consciousness which this process instilled in me. As physical therapists, it is your responsibility to make the individual aware of the defects he/she must overcome; but somehow in the process there also has to be the creation of an awareness that the total human being is competent, nice to be around, more like than different from other people, and well deserving of feelings of selfworth and self-respect.

This presentation probably has been different from the expectations of the Conclave's program planners. Certainly, a critique of physical therapy approaches to the patient cannot be anticipated in a panel discussion on "Making Adjustments to Disabilities." People with disabilities are continually confronted in their daily lives with the conscious and unconscious biases of others. These biases are instilled in each of us from our first moment of social contact. Not only must the disabled be trained to cope with them and succeed despite them, but attitudes must universally change. I believe such change can occur only when we heed the prescription of the sage who said "No man can change the world. Each man can change himself, thereby changing the world."

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\*\*\*Speech to New York State Head Injury Association,  
December 14, 1982, Albany

One of my most vivid childhood memories is of an outing to Yankee Stadium on Lou Gehrig Day. My favorite uncle and aunt, their four children, my parents and I all attended. As we gathered that morning for brunch, the conversation centered around the tragedy of this world famous athlete becoming totally disabled. After listening for over an hour, I suddenly burst forth with, "Sure it is a tragedy, but how much greater is the tragedy for those persons who can never be an athlete, who can never have fame and fortune, who can never hope to achieve what he has achieved." With that, I stormed out of the room.

As my mother put me to bed that night, she told me that after I left the room, my uncle said that my remarks were the stupidest which he had ever heard me utter. Since he was not only my favorite uncle, but also a man of great learning, compassion and wisdom, knowing that he considered my comments "stupid" bothered me for years. Why were they stupid? The discovery of the answer to that question was the greatest professional lesson in my nearly forty years of clinical practice among persons with all types of disabilities.

Your children are different. Your children know what they are missing. In theoretical-neurological physiology, it is believed that they are better able to approach normalcy of functions through rehabilitation than we who were born with a defective central nervous system. In all practicality, this may not generally happen because of countless other variables.

As I thought of what I could say to you tonight that would be of maximum benefit, it seemed to me that I should first sort the issues into several categories -- each of which is greatly oversimplified:

Your children's problem -- There is a period of bereavement for the loss of their normalcy. Part of them has died and like in any death, the person must go through the five steps of grief. One of the steps is anger. One of the results of



their injury is trouble expressing their wants, needs and emotions, another is that their emotional displays are highly confused and distorted. It is, therefore, particularly difficult for them to progress through this step of the grief process.

They are now what they may have rejected in the past. Each of us has unconscious biases toward the disabled. It may be that the fact of their disability, rather than the physical limitation caused by their brain damage, had led them to devalue themselves as a person. Added to this is the absence of a long-range plan. To them, they have been doomed to a life of dependency, and no one can give them a right to hope for anything else.

You as parents -- It is well documented that parents of a disabled person experience their own grief process. While it is separate and distinct from that of your child, it is similar in nature. What we have learned over the course of the last three or four decades is that parents must receive support and help in processing through the steps of bereavement to enable them to cope with the realities that may now exist. Needless to say, this is easier to do with the parent whose young child is disabled than it is with the parent whose bright, beautiful, normal child suddenly becomes incapacitated in the prime adulthood.

In the early steps of the grief process, the individual focuses upon the tangible, immediate problems -- walking, talking, feeding. As time goes on, the burden of having a grown person revert to previously outgrown actions and behavior requires you to totally reorient your life-style, your life-goals and relationships with others. This becomes more and more difficult to bear. Yet, the only help you get, if any, is with the tangible.

Professionals -- In seeking help, your first support comes from medically oriented people -- doctors, nurses and physical, occupational and speech therapists -- and you focus on what I call the tangibles. In the guise of devil's advocate, I ask, "To what end?" When does illness end and working toward productive living begin?

Government -- Government's role in dealing with adolescents and adults who become disabled, as well as with per-

sons in certain categories of disability such as the deaf and hearing impaired, is historically confusing. Fifty to sixty years ago, most people became disabled in adulthood as a result of war or industrial accidents and their problems were, therefore, taken care of either through the Veterans Administration or Workers' Compensation. Laws and structures were thus provided to meet the needs of children with disabilities, but -- except for vocational rehabilitation -- not for persons past the age of 21. As medical science improved and life spans lengthened, alterations had to occur and programs were developed for frail/elderly and mentally retarded and developmentally disabled people, to name but two. These were, however, categorical and not philosophical expansions.

In other instances, there has been a conceptual carry-over from one disability group to another, as if each required the same approaches to return to productive living, the only differences being in some of the strategies and modalities used for the individual patient. We assume, for example, that if the individual cannot walk, a licensed physical therapist must provide physical therapy; if anything happens to alter the persons speech and language, only a certified speech pathologist can answer the need. Perhaps these assumptions should be re-examined. Perhaps, from the viewpoint of restoring productive living, new strategies and new alliances must be forged.

How are we going to achieve a philosophical expansion and service integration rather than service expansion in an era of limited resources? Only through an organization of people like you can agencies on both the state community level resolve these issues.

As State Advocate for the Disabled, I have made a personal commitment to telling it as I know it is, not as the audience wants to hear it because I feel that if we understand what the issues really are, we can resolve them.

## **From the Advocate's Desk**

"A woman from Union City, New Jersey, who is confined to a wheelchair won the right yesterday to take part in the (St. Patrick's Day) parade after complaining to the New York State Division of Human Rights. In a stipulation in State Supreme Court in Manhattan, the parade committee said that its ban on wheeled vehicles had not been intended to exclude handicapped persons."

This quotation from the March 17, 1982 issue of the New York Times is an example of systems advocacy. The woman from New Jersey called the Advocate's Office for assistance -- and was put in contact with the Division of Human Rights. The Advocate's Office also contacted the Mayor's Office for the Handicapped, the Governor's Office and a variety of other state officials and agencies to augment the case. State Human Rights Commissioner Werner Kramarsky should be praised for the immediate, definitive response which his office pursued.

So often people with disabilities confront staff of this office with the question, "What do you do for me?" Usually this question is not satisfactorily answered, nor can it be. Nearly 90 percent of what a systems advocacy office does is not visible.

At any given point in time, the staff of this office is working on at least a dozen specific issues raised by people with disabilities. What they need are results, not words. What is needed in all resolutions is action, negotiation and educa-

tion for mutual understanding. These are things done behind the scenes, not in a spotlight. These are things that are only meaningful when change is produced.

We win some and we lose some. Even when issues are resolved, seldom do we have an opportunity to show a direct line between what we did and the results. We are never the provider agency or the agency with prime responsibility for obtaining the resolution. We are, however, the catalyst for such resolution.

Of greater importance are those issues we fail to resolve; for then, we must understand the reason why we failed and seek compromise that will lead to ultimate resolution. In some instances, the strategies were improper; in others, a giant step has been sought when only a baby step is feasible.

We hear you. We are seeking resolution. What have we done for you lately? Call us. We'll tell you. (April 1982)

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During the most recent session of the New York State Legislature, I experienced a period of maximum learning and, as is typical in all such learning experiences, I felt overloaded. All the lessons learned have not been absorbed. The legislative process is so intricate, unpredictable and, in some ways, nebulous that it defies description. As many of you have learned along with me, nothing can ever be assumed, no detail can be overlooked and what is true one day may not be valid the next.

I have a sense of great accomplishment. Laws were passed that hold real meaning for people with disabilities. The tremendous, constant efforts of so many people are the reasons why civil rights for persons with disabilities, independent living, the Office of Advocate's legislative base, respite, promotional opportunities under Section 55-b and the Mental Health Services Council were passed by the legislature. Yet, I feel some frustration, much like the student who received a final grade of B+ in a most difficult course and then realizes that, with some additional effort, an A could have been at-



tained. At this moment, however, I do not know what that additional effort could have been.

In recent months, I have frequently asked, "Who is the enemy and why?" Why did the nondriver ID fail? It was needed by the disabled, the aging, the retail merchant, the restaurant owner, the parent. Proof was presented that fees would reimburse the state's start-up costs in less than one year. It was a governor's program bill. There were support letters from many diverse state agencies. In fact, the combination of agencies supporting this bill was a rarity in the annals of state government. It looked like "apple pie and motherhood."

Essential bills often fail to become law for reasons other than the merits of the bill or its financial impact. Both as a clinician and as a person with a severe disability, I believe that the most important initiatives pending before the legislature were the early childhood education bills. I would do anything to minimize the impact of disabilities on the individual, the family and the taxpayer. I know from personal experience that early intervention is the only way to do this. I know of no legislator, government official, service provider, teacher, early childhood educator or informed citizen who disagrees. After 14 years of a variety of proposals to begin to meet this need, neither pending bill had the universal support of all interested parties. In fact, both were drafted by consensus. It is hoped that, during the next session, a new approach can be presented which will receive the support necessary for passage.

Too often, what is demanded is too much to have enacted at one time without a detailed, staggered plan for implementation. Equity demands that the rights of all New Yorkers, including all taxpayers and persons with all types of disabilities, be given equal consideration. It is a commonly known fact in capital cities of this nation that too frequently bills are passed in one house of the legislature with the prior knowledge they will never be reported to the floor of the other house. This "good guy/bad guy" has been played for years with some very basic legislation. Games will continue until we, acting in coalition, learn how to stop them.

In the last days of a regular session of the New York State Legislature, the pressure builds beyond description. In the waning hours of the legislative session, time often does not permit passage of essential bills by both houses, even when there is agreement that such legislation is necessary.

Finally, I am most grateful for the efforts which were expended by and on behalf of persons with disabilities during the 1981-1982 session of the legislature. We have networked and wrought miracles. It would take an issue of 'The Advocate' to list all the contributors to these joint efforts. While any partial list risks offending those who are omitted, I cannot resist showing off. Among those who acted together are the following organizations and their individual members: New York State Association of Retarded Children, New York State United Cerebral Palsy Association, the New York State Association of Rehabilitation Facilities, the New York State Legislative Coalition of Persons with Disabilities, the various local councils on the disabled and offices of the handicapped, Eastern Paralyzed Veterans Association and on and on ad infinitum. I applaud and thank each and everyone for a superb job. (August/September 1982)

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The New York Times ran an article on September 13 entitled "Handicapped Pupils Join the Mainstream" that described the commendable strides the Yonkers School District has made in transitioning moderately, physically disabled children into regular classroom settings. The same article discussed how parents have become upset because they perceive proposed changes to federal regulations implementing P.L. 94-142 will present an imminent threat to their children's progress and educational rights during this and the next school year.

I think the record should be set straight. While New York State's programs for children with handicapping conditions must be consistent with applicable federal regulations in order to qualify for federal aid, the actual delivery of services in this state is governed by Article 89 of the New York State

Education Law and the implementing regulations of the commissioner of education (8NYCRR Part 200). In fact, the federal government contributes only four cents of every dollar spent on the education of children with handicapping conditions.

What advocates for and, in this instance, parents of children with disabilities should be concerned about is the quality of that education and the preparation that is given the child toward growth as a self-respecting, self-supporting contributor to the community. Regardless of what changes occur in P.L. 94-142 regulations, the concerns and energies of New Yorkers must be sensitive to practices used to enforce current standards and any modifications which would detract from the quality of education.

Of equal concern to me, in view of the fact most advocates for the disabled know that we are governed by our own state laws, is that unnecessary hysteria continues to be generated for unclear purposes concerning the proposed changes. Although most people view present threats to P.L. 94-142 and other federal programs for persons with disabilities as originating in the obtuse, supply-side philosophy of Reaganomics, the record indicates that attacks on programs which were founded in the "apple pie and motherhood" tradition of over 40 years of federal legislation, have mounted in response to complaints from such national groups as the Association of School Boards, teacher's unions and the national conferences of governors and mayors. If the battle is to be won, it must first be understood who the enemy is.

Finally, change must occur. A law and its regulations conceived in the late 1960's and early 1970's -- based solely on a theory of what it should be as opposed to being products of a solid base of experience -- must continually evolve in order to be responsive to current and future needs. Let us have the wisdom and the strength to put forth the concerted effort required to develop these changes so as to ensure that every person in New York State with a disability is fully integrated into the daily life of the community by the year 2000. (October/November 1982)







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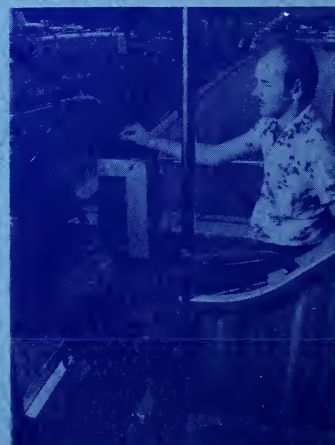
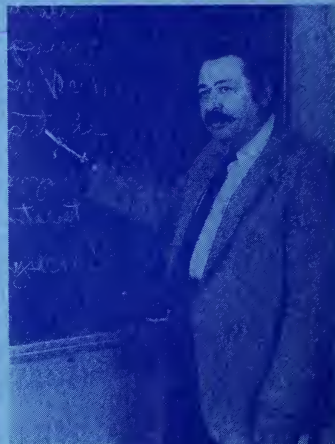
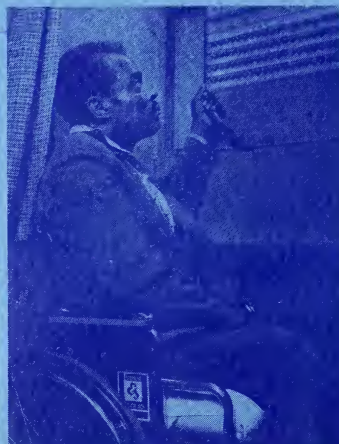
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